



BETTER CANCER CARE, AN ACTION PLAN

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FOREWORD by Ms Nicola Sturgeon



Cancer will affect most of us at some stage in our lives, be it personally or through the impact it has on a family member, friend or colleague.

Rapid advances in diagnosing cancers and assessing responses to treatment, population screening programmes that identify some cancers at earlier stages, new treatment techniques and advances in radiotherapy, surgery and chemotherapy all mean that cancer is now very often a long term condition. Many people live with and survive cancer and this brings with it a range of physical, social, emotional and often financial challenges.

Better Cancer Care spells out the actions that we believe are required to support all those in Scotland who find themselves living with and beyond cancer. It confirms that cancer remains a national clinical priority for NHSScotland and looks to partnerships with a range of stakeholders, including the voluntary sector, to improve outcomes for all those who are affected by cancer. This includes a clear commitment to strengthen our approach to cancer prevention and tackling inequalities in both access and outcomes across Scotland.

The response to the national discussion around this plan was excellent. We received around 150 responses, from patients, carers, healthcare professionals, the voluntary sector and other organisations. We also had face-to-face discussions at 19 'road show' events throughout Scotland and a highly successful national conference that was attended by approximately 350 delegates. This plan has been shaped by feedback received and we have used quotations from respondents throughout the document to give a flavour of what we heard.

There is already much to be proud of about cancer care in Scotland and I believe this plan will build on our achievements and further improve services in the future.

A handwritten signature in black ink that reads "Nicola Sturgeon".

Ms Nicola Sturgeon, MSP
Deputy First Minister and Cabinet Secretary for Health and Wellbeing

FOREWORD by Dr Harry Burns



Scotland's cancer record continues to improve and we are seeing significantly increasing survival rates for many cancers. *Better Cancer Care* sets out opportunities for us all to take actions which may reduce our chances of being diagnosed with cancer. Smoking, obesity, alcohol, sunburn and a poor diet all contribute to the risk of cancer. Since 2003, there have been improvements in cancer survival for those living in poorer areas. Nevertheless, deprivation remains one of the key risk factors for cancer. Uptake of screening programmes for cancer among those living in deprived areas is lower than those who live in wealthier areas.

In addition, there is a need to focus on the quality of care we are providing to the people of Scotland – this encompasses clinical outcomes, improving the way people experience care and ensuring that we spend NHS resources in the best way possible to meet the needs of those with cancer and their carers.

The next decade will see continued research into the causes and treatments for cancer and this plan sets out how we can support this process in Scotland. We want to ensure that our services are world-class and this plan sets out a number of ways to achieve this. We need to ensure our workforce is highly skilled and responsive to the needs of patients. There will be new ways of delivering services which we need to take full advantage of to improve patient care.

The delivery of this ambitious plan requires joint working at national, regional and local level. I have asked Dr Aileen Keel CBE to chair the new Scottish Cancer Taskforce that will oversee the delivery of this plan and I am determined that medical professionals across our country continue to provide clear clinical leadership as we implement its recommendations. Success will, of course, depend upon much broader cooperation. Patients, carers, NHSScotland, local authorities, universities, the Scottish Government, Royal Colleges and the voluntary sector all have a critical role to play. By working together we can address those cancers that can be prevented, detect cancers as soon as possible, provide high quality diagnosis, referral, treatment and follow up and support the ever increasing number of people in Scotland who are living with and beyond cancer.

A handwritten signature in black ink, appearing to read "Harry Burns".

Dr Harry Burns
Chief Medical Officer



EXECUTIVE SUMMARY

The Challenge for Scotland

Projections show that the number of people diagnosed with cancer is likely to rise to nearly 35,000 per annum between 2016 and 2020. This compares to around 30,000 patients per year between 2006 and 2010, reflecting the impact of Scotland's ageing population as well as improvements in diagnosis. More people will be living longer after their cancer diagnosis. There is therefore a need to ensure that appropriate rehabilitation and support services are in place. Targeted action continues to be a requirement to tackle persistent levels of inequality. People living in deprived areas are more likely to be diagnosed with cancer and have a higher death rate than those who live in more affluent areas.

Prevention

Lifestyle factors such as smoking, poor diet, physical activity, obesity and excess alcohol consumption are important modifiable factors that contribute to the risk of getting cancer. The Scottish Government is implementing a wide-ranging programme of action to encourage healthy lifestyle choices, with a particular focus on tackling health inequalities. Community Health Partnerships have a critical role to play in ensuring an integrated response to these challenges which reflect the particular demands of local communities. The roll-out of the Human Papilloma Virus (HPV) Immunisation Programme, represents a significant step forward in tackling cervical cancer.

Early Detection of Cancer

The earlier that cancer is diagnosed, the better the chance of a complete cure. The Scottish Government is committed to an evidence-based approach to screening, based upon the advice of the UK National Screening Committee and National Advisory Group in Scotland. The national screening programmes for cervical, breast and bowel cancers play a critical role in the national cancer strategy and opportunities will be taken to heighten public awareness of these programmes and target those groups who are less likely to attend or complete a screening programme. Screening programmes will continue to be developed in line with best practice. The Scottish Government is supporting the roll-out of the Scottish Bowel Screening Programme which will be fully implemented by the end of 2009.

Genetic and Molecular Testing for Cancer

A small number of cancers are caused by inherited genes that predispose an individual to a particular form of cancer, but it is increasingly understood that most, if not all, cancers arise from changes to the genetic material in individual cells. Scotland has a coordinated cancer genetic service based at four regional genetic centres and investment will ensure more genetic consultants, genetic counsellors, scientists and appropriate psychological support in order to further strengthen this service. A short-life working group including patients and other key stakeholders will also be asked to advise the Scottish Government on ethical issues surrounding consent, storage, and access to tissue samples.

Referral and Diagnosis

Key components of successful cancer management include early recognition and reporting of symptoms, expertise in identifying patients requiring prompt referral and rapid access to investigations and treatment. The Scottish Government will work with the Scottish Primary Care Cancer Group, NHS Health Scotland, health promotion teams, voluntary groups and others to assess how to improve public awareness of common cancer symptoms and encourage patients to present early. Priority also needs to be given to the development and auditing of electronic referral systems within NHSScotland to ensure that patients are referred quickly and appropriately between primary, secondary and tertiary care.

Treatment

Cancer treatment can involve surgery, radiotherapy and chemotherapy or any combination of the three within a coordinated treatment plan. Effective service and workforce planning is required to ensure the appropriate capacity to deliver such treatments. This will be supported by regional and national audits, appropriate information systems and Managed Clinical Networks. Improvements will be made in horizon scanning to assess new opportunities to ensure that patients in Scotland continue to benefit from the latest technologies and techniques. Further action will be taken to improve the transparency and accessibility of the arrangements for introducing new cancer drugs into NHSScotland.

Living with Cancer

As Scotland's population ages, treatments advance and screening programmes prove increasingly effective at detecting cancers at an earlier stage, many more people will find themselves living with and beyond cancer. Many people affected by cancer in Scotland experience significantly lower levels of financial income as a direct result of their cancer diagnosis. The Scottish Government will work with the voluntary sector to improve the information and advice that is available to help them manage their conditions, sustain employment and access the benefits and support to which they are entitled. Funding will be provided through the new self-management strategy for Scotland to support a range of projects and organisations that support people to maintain their independence as much as possible and become genuine partners in the design and delivery of their care.

The publication of *Living and Dying Well* provides the basis for taking forward previous recommendations made by the Scottish Partnership for Palliative Care and Audit Scotland. For the first time Scotland now has a single, comprehensive approach to the development of palliative and end of life care services.

Improving Quality of Cancer Care for Patients

A wide-ranging approach to quality improvement is required in order to ensure that services are patient-centred, safe, effective, efficient, equitable and timely. *Better Together*, the new Scottish Patient Experience Programme, will prioritise action to improve cancer services on the basis of feedback from patients. By 2010, all of Scotland's tumour-specific networks will take part in national audit that will enable an ongoing programme of improvements to clinical practice, based on national indicators which allow benchmarking against other countries' approaches. As part of the programme of change designed to introduce the 18-week Referral to Treatment standard throughout Scotland by 2011, a new 31-day target will be introduced for cancer patients covering the period from the decision to treat to the start of treatment.

Delivery

The delivery of this ambitious plan requires strong and effective clinical and managerial leadership. A new Scottish Cancer Taskforce, chaired by the Deputy Chief Medical Officer, will oversee the implementation of the actions in this plan and will be charged with ensuring that the network of advisory and delivery groups is streamlined and fit for purpose.



SECTION ONE:

THE CHALLENGE FOR SCOTLAND

1. THE CHALLENGE FOR SCOTLAND

Cancer Incidence

Every year, about 27,000 people in Scotland are told that they have cancer. Lung, prostate and large bowel cancers account for approximately 53% of all cancers in men (Figure 1) whilst breast, lung and large bowel cancers account for 55% of all cancers in women (Figure 2).

Figure 1: The most frequently diagnosed malignancies in men in Scotland in 2005

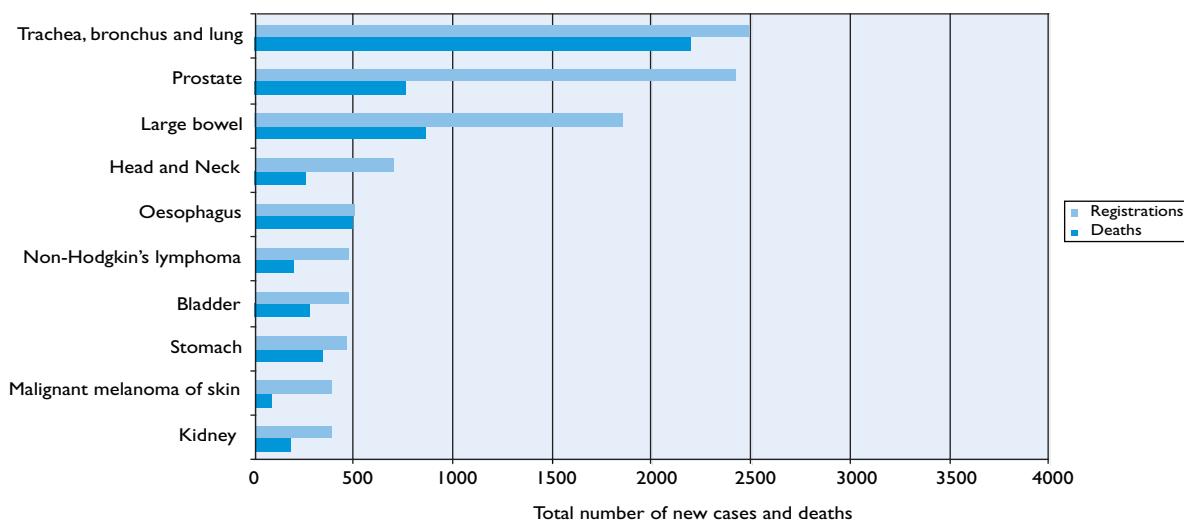
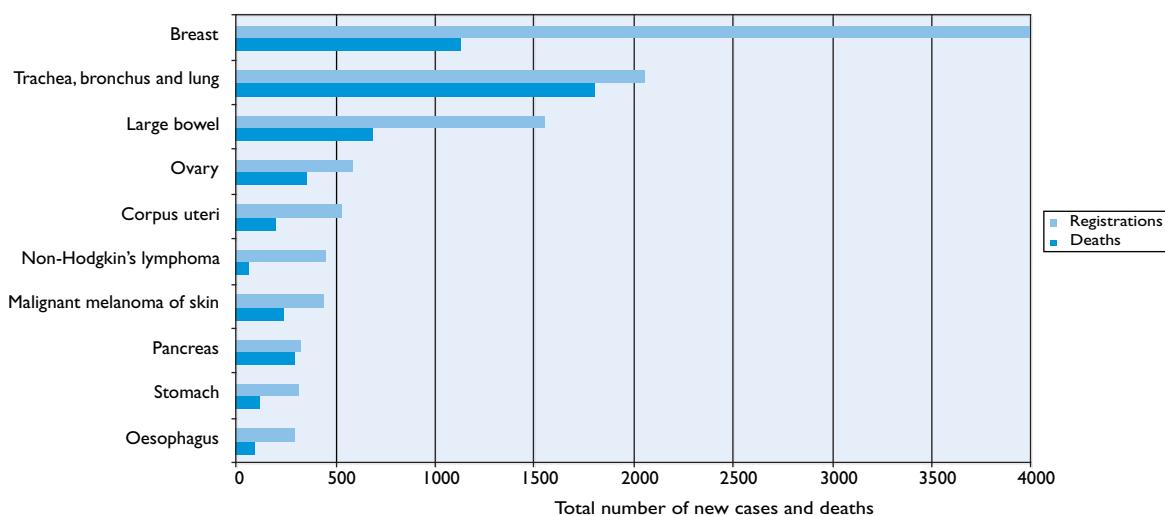


Figure 2: The most frequently diagnosed malignancies in women in Scotland in 2005



Figures 1 and 2 exclude non-melanoma skin cancers.

Data Source: ISD

The total number of people diagnosed with cancer is increasing year on year, largely due to the increasing number of elderly people in the population and the fact that life expectancy is increasing. Cancer Scenarios published in 2001 and updated in 2004 and 2008 (2008 publication available on www.scotland.gov.uk/bettercancercare), sets out projections for the incidence of cancer as the basis for assessing and planning future cancer services in Scotland. Based on the trends observed between 1961 and 2000 and current population projections, Cancer Scenarios predicts that the number of cases diagnosed per annum is likely to rise to almost 35,000 in 2016-2020 (Table 1). Such projections may, of course, change if there are fundamental shifts in the size or age profile of Scotland's population or if further action is taken to encourage adoption of lifestyle changes that minimise risks.

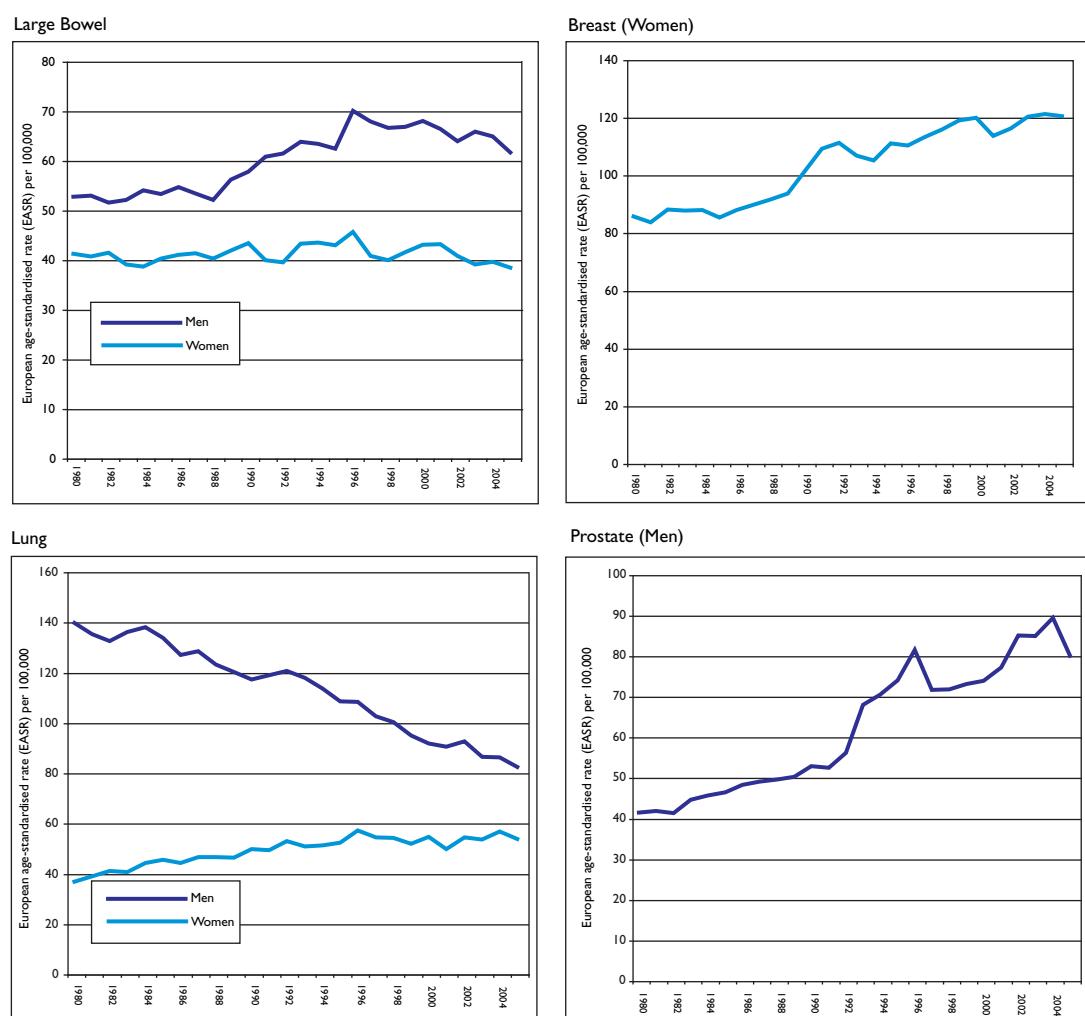
Table 1: Projected number of new cases by cancer site

Cancer Site	Projected new cases			
	2006-10	2011-15	2016-20	Difference in total (number) projected new cases between 2006-10 and 2016-20
Head and Neck	5,986	6,377	6,796	810
Oesophagus	5,032	5,739	6,641	1,609
Stomach	4,140	4,013	3,846	-294
Large bowel	20,388	22,783	25,579	5,191
Lung	22,002	21,532	21,518	-484
Pancreas	3,596	3,876	4,246	650
Malignant melanoma of the skin	4,398	5,190	5,991	1,593
Breast	20,841	22,331	24,431	3,590
Cervix	1,378	1,211	1,041	-337
Corpus uteri	2,523	2,755	3,024	501
Ovary	3,764	4,090	4,420	656
Prostate	11,803	13,864	16,034	4,231
Testis	1,191	1,313	1,432	241
Renal	3,636	4,196	4,870	1,234
Bladder*	8,700	9,384	10,171	1,471
Brain, meninges and CNS	1,976	2,122	2,298	322
Hodgkin's disease	687	700	727	40
Non-Hodgkin's lymphoma	5,517	6,384	7,378	1,861
Leukaemia	3,656	4,042	4,488	832
Other and unspecified	17,440	18,621	20,050	2,610
Total five-year period	148,654	160,523	174,981	26,327
Average per annum	29,731	32,105	34,996	5,265

* Includes carcinoma in situ and neoplasms of uncertain or unknown behaviour of the bladder.

Changes in the absolute numbers of cases of cancer are important in the context of health service planning, but they cannot be used on their own to predict the risk of developing cancer among the population. It is necessary to calculate age-standardised rates to assess how risk changes over time. Rates of breast and prostate cancer continue to increase, while rates of large bowel cancer have declined in recent years. Lung cancer rates have fallen amongst men and appear to be reaching a plateau for women (Figure 3).

Figure 3: Trends in European age-standardised incidence rates for large bowel, breast, lung and prostate cancer; Scotland: 1980-2005



Age-standardised rates are adjusted to take account of changes in the age structure of the population over time.

Data Source: ISD

Cancer Incidence – Paediatrics and Young People

Every year, approximately 130 children aged 14 years and under are diagnosed with cancer in Scotland. This accounts for less than 1% of all cancers diagnosed at all ages. There has been a small, but statistically significant, increase in the incidence of childhood cancer from 108 per million children during 1975-1979 to 132 per million children during 1995-1999. The underlying cause of this increase is largely unexplained, although it continues to be the subject of ongoing research.

There are also 60 new cases of cancer each year in the 15-19 year age group. The most common types of cancer in this age group in Scotland are lymphomas and leukaemias. This is in contrast to younger children, where the relative frequency of different types of cancer is more evenly distributed.

Survival from Cancer

Survival is lowest in patients with cancers which often present at an advanced stage and are less amenable to treatment. These include cancers of the pancreas, lung and oesophagus. In men, survival at five years after diagnosis varies from under 5% for cancer of the pancreas, to over 95% for testicular cancer (Table 2). Equally, survival tends to be better for cancers where patients are more likely to present at an early stage. Examples include cancers of the uterus, bladder, thyroid, and malignant melanoma of the skin. Improved survival is also seen in cancers which can be detected early by screening programmes (such as, cancers of the cervix and breast) and for cancers where there have been major advances in treatment (such as, cancer of the testis and Hodgkin's disease).

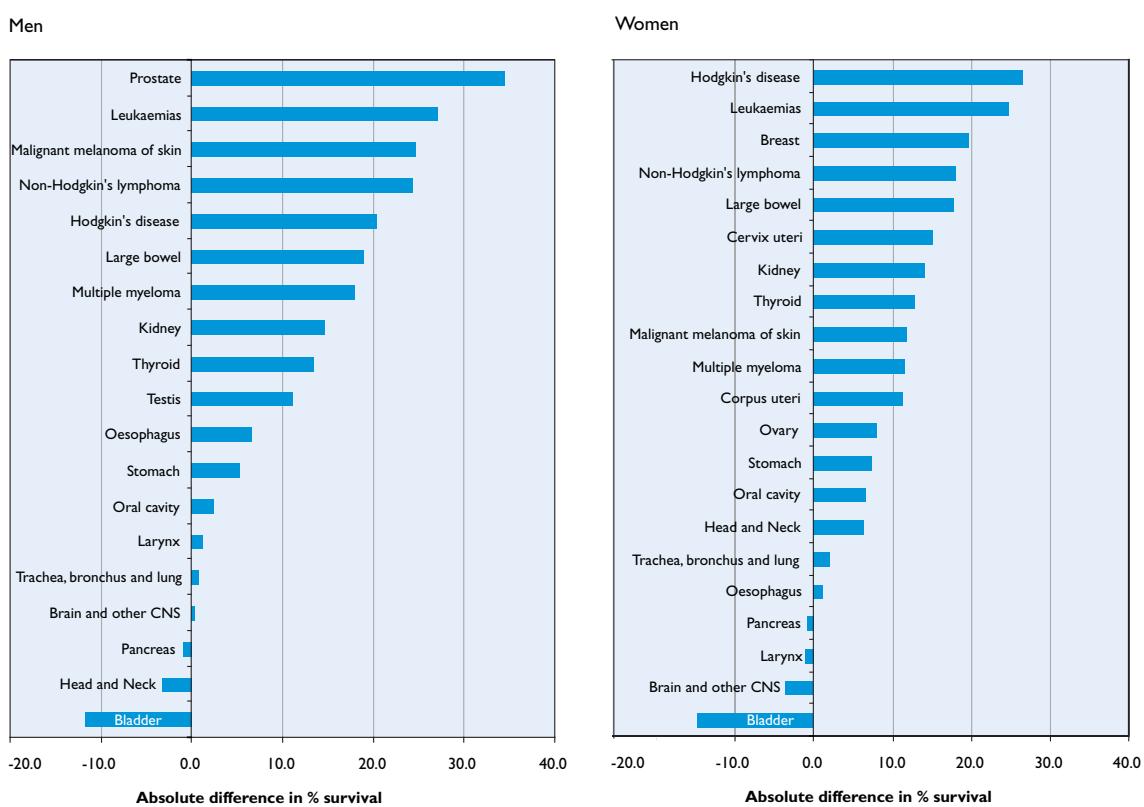
Table 2: Five-year relative survival (%) for patients diagnosed in the period 2000-2004 ages 15-99: by cancer and gender

Cancer Site	Men (%)	Women (%)
Oral cavity	47.9	61.6
Head and Neck	54.7	60.7
Oesophagus	11.0	7.7
Stomach	14.0	16.0
Large bowel	54.9	53.9
Pancreas	2.7	2.7
Larynx	67.1	58.8
Trachea, bronchus and lung	7.0	7.8
Malignant melanoma of the skin	86.5	92.8
Breast (Women)		83.7
Cervix uteri		68.5
Corpus uteri		82.9
Ovary		38.1
Prostate	80.1	
Testis	97.2	
Bladder	53.6	41.5
Kidney	50.1	44.9
Brain and other CNS	12.4	13.0
Thyroid	80.8	91.5
Non-Hodgkin's lymphoma	59.1	59.5
Hodgkin's disease	89.0	91.9
Multiple myeloma	33.9	32.0
Leukaemias	53.0	50.0
All malignant neoplasms (excluding non-melanoma skin cancer)	42.2	51.0

Data Source: ISD

Between 1980-84 and 2000-04, almost all cancers showed improvement in survival five years after diagnosis (Figure 4) and for some cancers this improvement was marked. For example, for malignant melanoma of the skin, survival increased from 62% in men diagnosed between 1980-84 to 87% during the period 2000-04, an absolute increase of 25%. This could be due, in part, to an increase in early stage diagnosis following health education programmes aimed at encouraging earlier presentation and referral.

Figure 4: Absolute difference^a in relative survival at five years by cancer and gender: patients diagnosed in 2000-2004 compared to those diagnosed in 1980-1984 (patients aged 15-99)



^a The change over the whole period is calculated as the difference between relative survival at five years in 1980-84 and 2000-04.
Data Source: ISD

Other cancers with large absolute increases in survival at five years are large bowel cancer (up by 19% for men and 18% for women), Hodgkin's disease (up 20% for men and 27% for women), and leukaemia (up 27% for men and 25% for women). The increase in survival observed for prostate cancer in the most recent periods is likely to reflect the use of prostate-specific antigen (PSA) testing. PSA testing may, however, result in misdiagnosis and result in the diagnosis of some less aggressive and possibly non life-threatening tumours (see prostate screening, page 37). The recent apparent decrease in survival from bladder cancer is a result of a change in disease classification and does not mean that fewer people are surviving in real terms.

Comparison with Other European Countries

Survival from cancer in Scotland is similar to that in England and in Wales, although survival from malignant melanoma of the skin is notably higher in Scotland. Scotland's survival from testis cancer is amongst the best in Europe, while survival for some cancers is lower compared with other European countries (Table 3).

Table 3: Five-year age-adjusted^a relative^b survival (%) for patients from selected European countries^c diagnosed with selected cancers during 1995-1999

Country	Site/type of cancer							
	Large bowel	Lung	Malignant melanoma of the skin	Breast	Ovary	Prostate	Testis	Hodgkin's disease
Scotland	51.5	8.0	88.4	75.0	31.6	67.8	97.8	78.6
England	50.8	8.6	84.6	77.6	30.3	69.8	95.6	79.1
N Ireland	51.8	10.2	92.1	77.4	34.0	60.8	95.1	74.0
Wales	50.6	9.0	73.6	76.9	32.3	68.7	93.3	75.4
Austria	56.7	13.9	82.1	78.5	42.8	84.9	94.7	78.5
Denmark	49.3	7.9	85.1	77.5	32.3	47.7	94.7	79.6
Finland	57.8	9.6	84.5	83.6	39.6	80.0	94.9	83.6
Iceland	57.3	14.7	83.9	87.6	30.5	79.8	N/A	N/A
Malta	51.2	8.7	82.7	75.9	30.4	71.2	98.3	N/A
Norway	58.3	10.9	87.3	82.5	37.8	74.5	95.1	83.9
Slovenia	44.2	8.8	79.6	71.9	33.4	58.2	95.2	82.5
Sweden	58.3	13.1	90.2	84.3	42.2	77.3	97.7	83.1

Data Source: Eurocare

^a To make comparisons more valid, survival estimates have been age-adjusted to allow for differences in the age structure of the populations of patients with cancer in different countries. Unadjusted estimates of survival may be higher or lower, depending on the cancer site/type.

^b The calculation of relative survival takes account of differences in background mortality in different countries, therefore focusing on survival from cancer.

^c Only countries with their total populations covered by cancer registration were selected.

Cancer Mortality

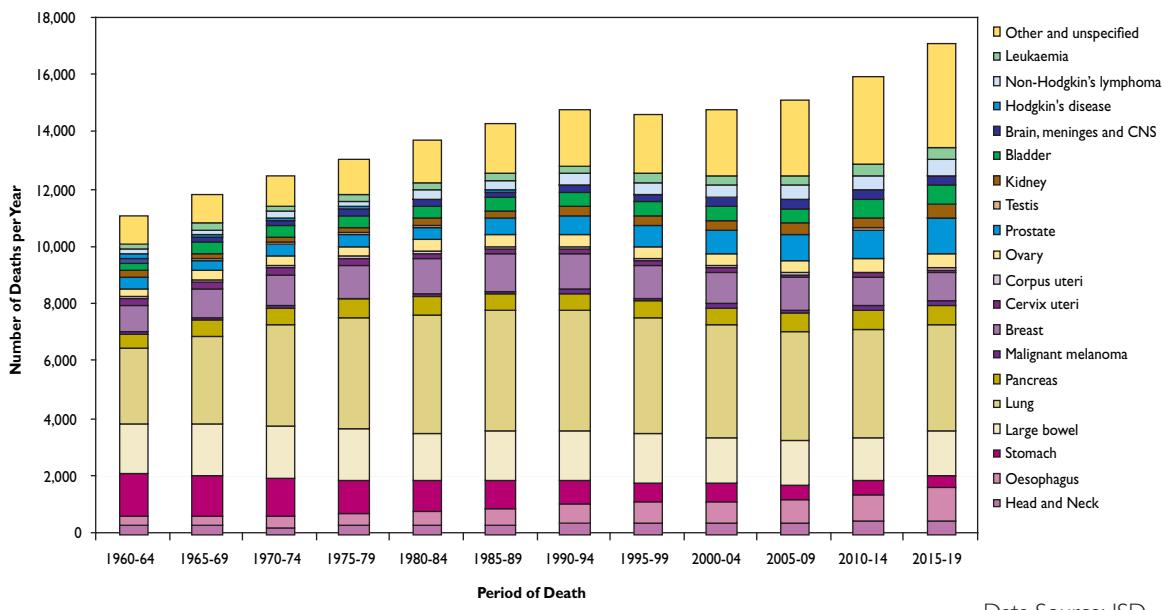
Over 15,000 people died of cancer in Scotland in 2007. Lung cancer accounted for the largest number of deaths in both sexes (29% in men, 25% in women). Large bowel, breast and prostate cancer were the other major causes of cancer deaths.

In the last decade, overall cancer mortality rates have decreased by 12% in men and 5% in women. In men, the largest falls in mortality from cancer have been in stomach, lung and large bowel cancer (29%, 22% and 19%). Death rates from prostate cancer, the second most frequently diagnosed cancer in men in 2005, decreased by 9%.

For women, the largest falls in mortality rates from cancer have been in stomach and large bowel cancer (37% and 17%, respectively). Death rates from breast cancer, the most frequently diagnosed cancer in women, have decreased by 12%, in spite of the increase in incidence of breast cancer in women. Cervical cancer deaths have also decreased by 32%.

Figure 5 shows the long-term observed and predicted trend in mortality by cancer site. It is predicted that, based on past and current mortality trends and projected changes in the population age structure, the *number* of cancer deaths will rise to around 17,000 per year in the period 2015-2019. Thus, although mortality rates have and should continue to decrease, the number of people in Scotland dying of cancer will increase as the population ages.

Figure 5: Observed and predicted cancer deaths by cancer site

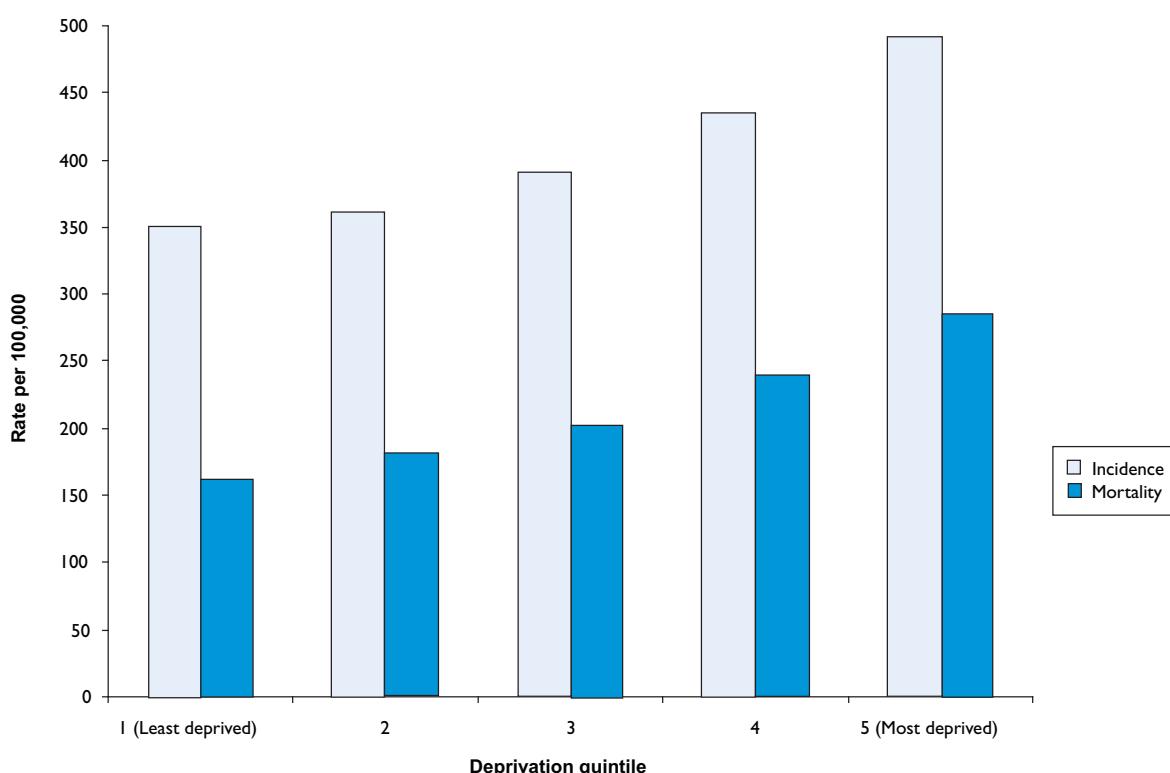


Data Source: ISD

Inequalities and Cancer

It is still the case that people living in the most deprived areas of Scotland have the highest risk of being diagnosed with cancer and the lowest chance of survival (Figure 6). Significant patterns exist when examining incidence and mortality rates by deprivation in Scotland. Considering all cancers combined, the most deprived areas report incidence rates almost 40% higher than the least deprived areas. Mortality rates for all cancers combined are approximately 75% higher in the most deprived compared to the least deprived areas. Only a few cancers have higher incidence rates in those living in the least deprived areas (for example, female breast cancer, prostate cancer and malignant melanoma of the skin).

Figure 6: All malignant neoplasms excluding non-melanoma skin cancer age-standardised incidence and mortality rates by SIMD (Scottish Index of Multiple Deprivation) 2006 deprivation quintile.



Source: Scottish Cancer Registry, ISD (incidence); General Register Office for Scotland (GROS) (mortality and populations)

There is some evidence that socio-economic inequalities in survival are widening over time. This may indicate a lower awareness of the symptoms of cancer, the benefits of early detection through screening and differences in healthy lifestyle choices by people living in the most deprived areas. A report on long-term monitoring of health inequalities produced by the Scottish Government in response to recommendations from the Ministerial Task Force on Health Inequalities

(www.scotland.gov.uk/Publications/2008/09/25154901/0) presented analysis of inequalities in cancer mortality amongst those aged 45-74 years for the period 1997-2006. The results suggest that whilst inequalities appear to have been relatively stable in absolute terms, there has been a widening of inequalities in relative terms because improvements in the most deprived areas have not been as great as those observed in the least deprived areas.



SECTION TWO:

PREVENTION

2. PREVENTION

Lifestyle factors such as smoking, poor diet, physical inactivity, the proportion and distribution of fat in the body and alcohol consumption are all important modifiable factors that contribute to an increased risk of getting cancer. Changing behaviours can affect the risks associated with more than one cancer as well as other diseases (such as heart disease and diabetes). Responses during Better Cancer Care consultation indicated that not all people believe cancer can be preventable.

"I don't really believe you can do much [to prevent cancer] and apart from good diet etc. to prevent cancer it has no respect for anyone, if cancer wants to strike any individual nothing will alter that. You have just to hope and pray you will not be the next victim."

Better Cancer Care Consultation Respondent

Recent European studies have suggested that addressing these lifestyle factors, coupled with improving life circumstances, can be effective in preventing cancer in the future. It is estimated that over half of all cancers might be avoided through such actions, which is often referred to as 'the preventable fraction'.

Tobacco

The evidence linking tobacco use to cancer is irrefutable, with smoking being strongly associated with cancers of the oral cavity, pharynx, larynx, oesophagus, pancreas, kidneys and bladder, as well as lung cancer. In 2004, among men, 40% of all cancer deaths and 91% of lung cancer deaths were attributable to smoking, while for women, the equivalent figures were 29% and 88%, respectively. Smoking also works together with other risk factors such as alcohol to multiply the risks of cancers of the oral cavity, pharynx, larynx and oesophagus. In the UK, an estimated 90% of lung cancer cases are due to smoking and there is clear evidence that stopping smoking is the single most important action that current smokers can take to reduce their risk of cancer.

Example of Good Practice in Scotland

It is recognised good practice that dentists opportunistically screen for oral cancer/precancerous conditions when examining patients, given that they are trained for and obviously well placed, to check mouths for such abnormalities. The number of adults registered with dental practices decreases after the age of 44, meaning that dentists have less access to those groups of patients who are at a higher risk of developing oral cancers (including older males who smoke and drink).

Significant progress has been made in recent years in shifting cultural attitudes to smoking, including through the introduction of a ban on smoking in public places in March 2006 and legislation to raise the age of sales for tobacco from 16 to 18 in October 2007. Whilst it is too early to assess the long-term effects of such changes, there are some extremely positive signs with, for example, one year after the legislation, an 89% reduction in exposure to second-hand smoke among bar workers (based on measurements of salivary nicotine, a marker of exposure to tobacco smoke).

The Scottish Government is determined to see a further reduction in smoking levels and is committing £42 million over the next three years (2008/09 to 2010/11) to support the wide-ranging programme of actions arising from *A Breath of Fresh Air for Scotland* including increased emphasis on preventing people from becoming smokers in the first place. *Scotland's Future is Smoke-free: A Smoking Prevention Action Plan*, published in May 2008, sets out an ambitious programme of measures designed specifically to discourage children and young people from starting to smoke and becoming regular smokers by reducing the attractiveness, affordability and availability of cigarettes and other tobacco products. Measures within this action plan include further legislative controls on the sale and display of tobacco products.

Example of Good Practice in Scotland

NHS Lothian has developed an innovative two-year pilot smoking cessation service, targeting patients with cancer, their families and their carers who are motivated to give up smoking following their diagnosis. Based on robust, international evidence, the pilot has clearly defined aims and objectives and if successful, could be replicated elsewhere in Scotland.

Diet and Obesity

Since the publication of *Cancer in Scotland: Action for Change 2001*, the evidence linking obesity and excess body fat to cancer has become much stronger. Avoiding excess body fat, modifying diets and increasing the consumption of fruit and vegetables are important factors to consider in any approach to cancer prevention.

Obesity is associated with a number of serious chronic diseases including certain cancers (breast, large bowel and kidney). Building on the continued delivery of the *Scottish Diet Action Plan and Physical Activity Strategy*, the Scottish Government has committed £56 million for initiatives dedicated to tackling obesity in *Healthy Eating, Active Living: An Action Plan to Improve Diet, Increase Physical Activity and Tackle Obesity*, published in June 2008. Actions are aimed at supporting people to make healthier choices in what they eat, to build more physical activity into their everyday lives and to maintain or achieve a healthy weight.

"It is important to include nutrition education as well as physical activity in the curriculum of children."

Better Cancer Care Consultation Respondent

It is essential that the focus on good nutrition begins at the earliest stages of a child's life. Scottish Government funding has been made available to ensure that maternal and infant nutrition is given a high priority, through a range of interventions. These include the encouragement to breastfeed, as there is strong evidence to suggest that breastfeeding protects the mother against both pre-menopausal and post-menopausal breast cancer and some evidence to suggest breastfeeding protects against ovarian cancer.

Hungry for Success is a programme which focuses on helping pupils make informed choices with their diet both within and outside of school. The Schools (Health Promotion and Nutrition) (Scotland) Act 2007 builds upon and reinforces Hungry for Success and health-promoting schools' policies. The Scottish Government has agreed with local government to extend free school meal entitlement to more families living in poverty. Starting in August 2009, entitlement for free school meals will be extended to all primary and secondary school pupils whose parents or carers are in receipt of both maximum child tax credit and maximum working tax credit, subject to the necessary legislation being passed. In addition, school meals will be provided to all primary 1-3 pupils from August 2010 (subject to the necessary legislation being passed by the Scottish Parliament), with the agreement of the Scottish Government and local government.

Cancer Risk and Lifestyle

- 71% of people did not know of the connection between cancer and body weight
- 64% of obese and overweight people were unaware that regular exercise could reduce cancer risk
- 48% of obese and overweight people did not believe that eating healthily could help reduce cancer risk.

Cancer Research UK (2006)

Physical Activity

“There is a need to address the perception that a healthy lifestyle is expensive.”

Better Cancer Care Consultation Respondent

Evidence suggests that physical activity can protect against a number of cancers, including colon and breast cancer. The minimum recommended levels of physical activity are 30 minutes per day on most days of the week for adults and one hour per day on most days of the week for children and young people. However, the most recent estimates of the Scottish population found that only 33% of women and 44% of men currently meet the recommended daily amount of physical activity. The Scottish Government is committed to achieving the goal of 50% of adults and 80% of children meeting the minimum recommended levels of physical activity by 2022. To do this, individuals must be supported to take a greater responsibility for their health by encouraging them and providing them with more opportunities to become more active. Working in partnership with a range of local and national organisations, access to physical activity will be increased in:

- Schools – through programmes such as Active Schools and Y-Dance, and the Schools (Health Promotion and Nutrition) Act 2007

- Communities – through programmes such as *Paths to Health*, *Jog Scotland* and *Girls on the Move*
- Homes – through initiatives such as *Play@Home*
- Workplaces – through initiatives such as the *Institute of Leisure and Amenity Management Healthy Living Award* and the support provided to local businesses by the Fitness Industry Association.

Alcohol

There is now a substantial body of evidence which links alcohol to cancer. Indeed Cancer Research UK suggests that alcohol causes about 6% of cancer deaths in the UK. As little as three units a day can increase the risk of cancer of the oral cavity, pharynx, larynx, oesophagus, breast and large bowel. Primary liver cancer can also be a consequence of chronic liver disease, mortality rates of which in Scotland are one of the fastest growing in the world. Current advice suggests that men should consume no more than 3-4 units a day and no more than 21 units a week and for women to consume no more than 2-3 units a day and no more than 14 units a week. This advice suggests that people should also have at least two alcohol-free days a week.

The Scottish Government's consultation on new proposals to tackle alcohol misuse closed in September 2008 and will be used to inform a long-term strategic approach to tackling alcohol misuse in Scotland.

Example of Good Practice in Scotland

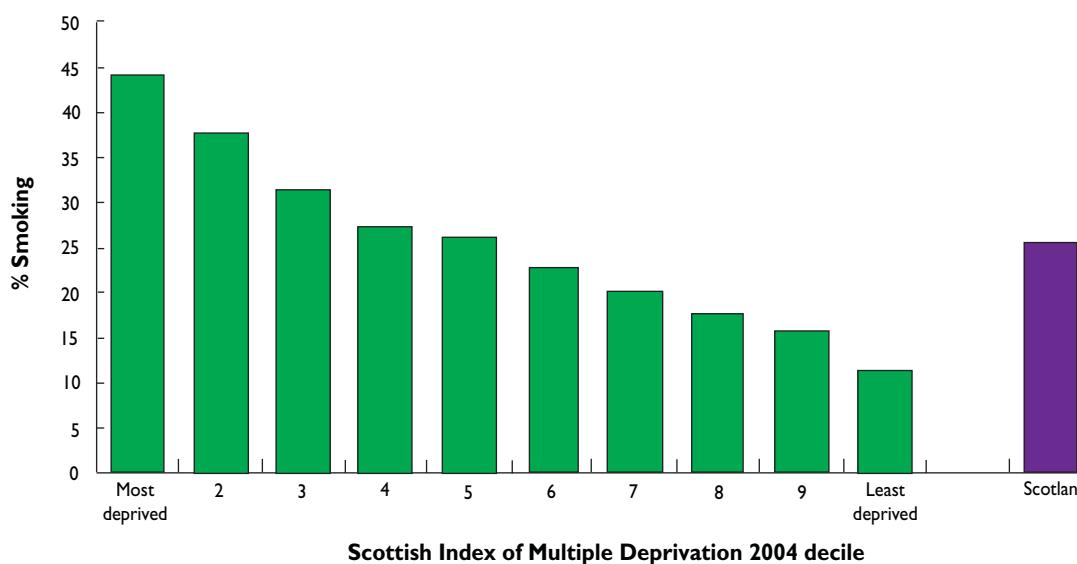
NHS Greater Glasgow & Clyde has developed a formal partnership with Glasgow City Council to manage and develop integrated alcohol and drug treatment services. The Addiction Services Partnership provides rapid access holistic care from health and social care professionals to individuals who have alcohol problems and who are at high risk of developing severe health problems including many alcohol associated cancers.

The Partnership has a range of services, including direct access to Community Addiction Teams, Community Alcohol Support Services, and it leads the implementation of screening and brief intervention programmes aimed at early detection of hazardous and problematic alcohol use. Nurse-led, supported detoxification programmes are available, aimed at helping patients reduce and/or cease their alcohol intake. A wide-ranging action plan is in place to assist acute services to better identify and manage individuals who have been admitted with alcohol problems.

Socio-economic Inequalities

Risk factors are known to vary by socio-economic status with, for example, higher rates of smoking amongst people living in deprived areas (Figure 7).

Figure 7: Prevalence of smoking by area deprivation, Scotland 2005-06



Data Source: Scottish Government

Equally Well made a series of recommendations to address health inequalities and indentified new Scottish Government funding of £15 million to reduce inequalities in the incidence of cancer and risk factors, such as smoking, as a priority. It encourages NHS Boards to play a leadership role in promoting good relations within communities, recognising the impact of discrimination and disadvantages on health, and the importance that social care pathways play for cancer patients. Community Health Partnerships should consider the potential for community pharmacies to reduce inequalities in health, by targeting services towards people living in the most deprived areas.

“Deprivation is an area where community pharmacies could have a key role.”

Better Cancer Care Consultation Respondent

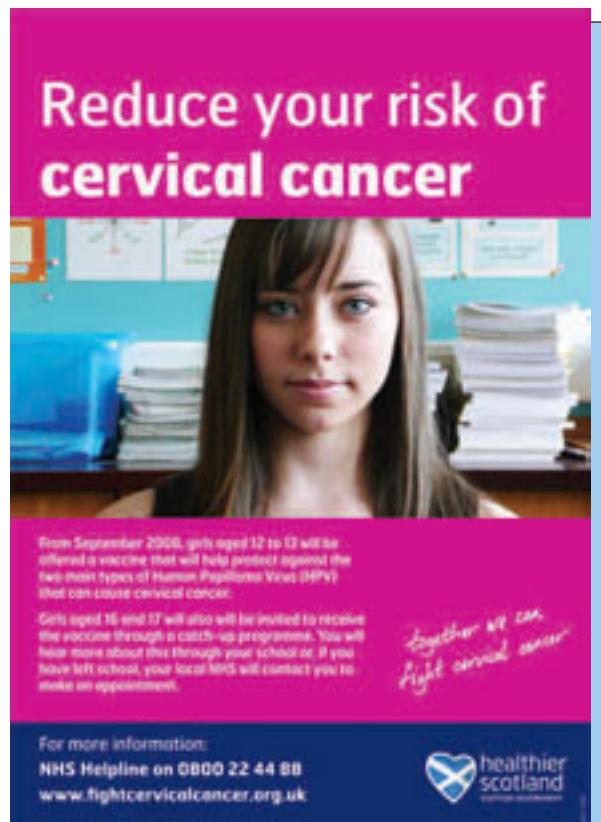
NHS Boards are creating hospital environments which create good health for patients, staff and visitors. The Health Promoting Health Service concept is that “*every healthcare contact is a health improvement opportunity*”. In March 2008, guidance was issued on health promotion action to be taken in acute care settings (CEL (2008) 14 *Health Promoting Health Service; Action in Acute Care Settings*). NHS Boards have been asked to implement specific health-promoting actions on smoking, alcohol, breastfeeding, diet and health and health at work, to support health improvement in acute care settings. Each action offers significant potential to improve health (including reducing the incidence of cancer) and to reduce health inequalities. Convenient locations, such as community pharmacies (for smoking cessation), will be used to encourage uptake.

Human Papilloma Virus (HPV)

Infection with the Human Papilloma Virus is a risk factor for cervical cancer and is mainly transmitted through intimate skin to skin contact during sexual activity. Two HPV vaccines have been developed which will help to protect teenage girls from developing cervical cancer later in life by protecting against the two HPV types that cause 70% of cervical cancers.

The Scottish Government has set aside £64 million over the next three years to implement an immunisation programme across the country. The routine immunisation programme for girls aged 12-13 began in September 2008. In total, around 210,000 girls will be offered HPV immunisation between 2008 and 2010. The 'catch-up' programme for girls aged between 13 and 17 years began in September 2008, and will be offered to girls over a period of three years.

This represents a significant step forward in improving Scotland's health and reducing cervical cancer. HPV immunisation will be delivered largely through schools. Girls who have left school will be contacted by their local NHS Board and offered immunisation. Even with this immunisation programme it remains vital that all women from the age of 20 continue to attend their cervical screening appointments, including those who have received the immunisation, as the vaccine protects against only 70% of virus strains that cause cervical cancer cases. Further information on HPV and the immunisation programme in Scotland is available on www.fightcervicalcancer.org.uk/



Excessive Exposure to Ultraviolet Radiation

The incidence of skin cancers in Scotland has increased significantly and malignant melanoma of the skin is now the ninth most common cancer in men and the seventh most common in women.

The primary recognised risk factor for melanoma of the skin is exposure to sun, especially but not exclusively, in childhood and adolescence. In addition, sunbed use provides a form of intense exposure to ultraviolet light. Just one session a month will double the average individual's annual dose of ultraviolet radiation, which is linked to increasing risk of cancer. Medical evidence on the use of sunbeds is increasing, with links to premature skin ageing, skin cancer, eye damage, photodermatoses and photosensitivity.

The Scottish Government is committed to improving public awareness about exposure to the sun and in recent years has supported the UK SunSmart campaign which highlights the importance of early detection, avoiding burning from sun exposure and the potential dangers of sunbeds. *The Public Health etc (Scotland) Act 2008* includes measures for controls on the use of sunbeds (which will come into force in 2009), as follows:

- A ban on operators from allowing the use of sunbeds by under 18s in commercial premises
- A ban on the sale or hire of sunbeds to under 18s
- A ban on the use of unsupervised or coin-operated sunbeds
- A requirement that sunbed operators give customers information on the health risks associated with sunbed use.

Occupational Exposure

Some cancers are linked to occupation; for example, exposure to asbestos in the workplace (such as the workplace for pipe fitters) is linked to the development, sometimes many years later, of mesothelioma (cancer of the lining of the lung).

Interim research from Imperial College London suggests that occupational exposures are responsible for around 4.9% of current deaths from mesothelioma, lung, bladder, nose and nasal cavity cancers, non-melanoma skin cancers and leukaemia combined. However, the researchers consider this to underestimate the true figure and further studies are being undertaken.

Occupational health and safety is a reserved matter, with responsibility for enforcement of occupational hygiene standards and control of occupational hazards residing with the Health and Safety Executive; these standards are enforced UK-wide. The Scottish Government will work with statutory agencies to further reduce occupational exposure of its population. Work is also taking place to estimate the burden of other cancers linked to occupation and potential occupational cancers due to more recent exposures. The work is scheduled for completion in November 2009 and the Scottish Government will take its advice into consideration after publication.

"The environments where people live and work should promote, not undermine, good health."

Better Cancer Care Consultation Respondent

Wider Environmental Issues

When considering the wider environment, the hazardous toxins of principal concern as known or probable carcinogens are radon gas from the ground, secondary tobacco smoke and diesel exhaust emissions. These toxins are all associated with an increased risk of lung cancer. The *Air Quality Standards (Scotland) Regulations 2007* set quality standards for air pollutants of principal public health concern, including those primarily linked to traffic, and established the mechanisms whereby air quality can be monitored and maintained against these standards. The UK Health Protection Agency is currently completing a detailed mapping exercise to establish the levels of radon in Scottish homes and once published, the Scottish Government will consider these findings and, where appropriate, act on them.

A potential for exposure to cancer-causing agents in food is well recognised. The Food Standards Agency is tasked with ensuring that the chemicals present in food do not compromise health and safety.

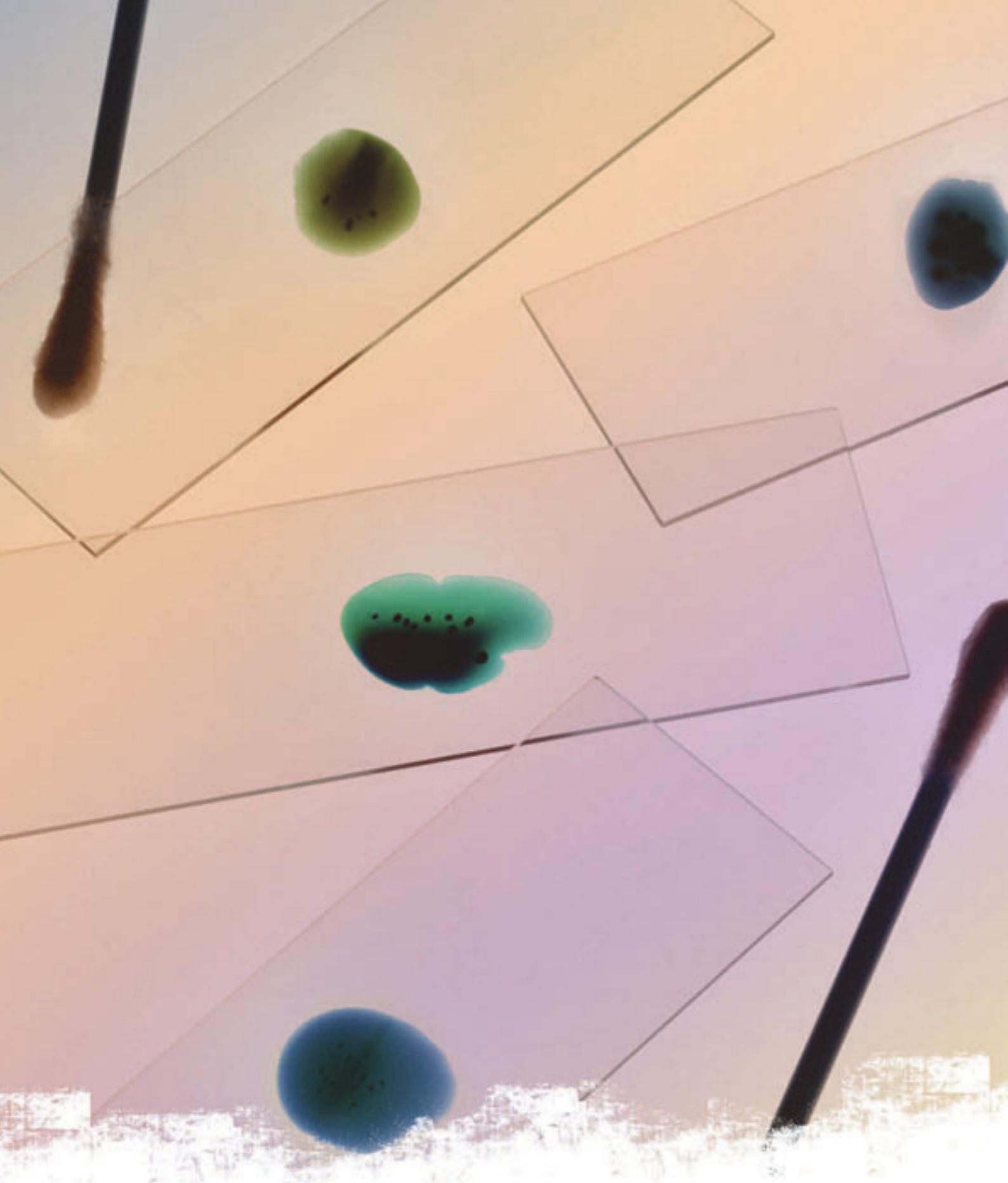
The *Strategic Framework for Environment and Health* initiative reflects a conviction within the Scottish Government that a smarter and more strategic approach is required, so that often quite subtle environmental influences on health can be addressed. Better understanding of the relationship between environment and health can promote a further reduction in health inequalities in Scotland. The Scottish Government is committed to funding research aimed at evaluating and improving the environment, including a research project which will develop tools and techniques to marshal and interpret evidence supportive of the new approach to policy on environment and health in Scotland.

Research into Cancer Prevention

The *National Cancer Research Institute Strategic Analysis Report (2002)* highlighted that only 2% of the total cancer research funding by National Cancer Research Institute partners was spent on cancer prevention research. This led to the establishment of the *National Prevention Research Initiative* aimed at improving health and preventing not only cancer but conditions such as cardiovascular disease, diabetes, obesity, stroke and dementia. This is supported by a wide range of government and voluntary sector funders. A total of £10.5 million has been spent so far, with ten of the 40 awards made being led by Scottish researchers. A further £12 million has been made available to support large research projects on behaviours associated with significant risks to health, such as poor diet, physical inactivity, smoking and alcohol consumption and on the environmental factors that influence those behaviours. This expenditure compares favourably to other parts of the UK.

We will:

- Continue to implement a wide-ranging and ambitious programme of action to reduce smoking levels in Scotland
- Expand entitlement to free school meals as part of a comprehensive approach to improve diet and tackle obesity
- Work with local and national partners to continue to expand access to physical activity
- Consider the findings of the national consultation on alcohol and publish an action plan for Scotland on tackling alcohol misuse
- Support NHS Boards to implement the recommendations of *Equally Well*, the report from the Ministerial Taskforce on Tackling Health Inequalities
- Consider the potential ways in which community pharmacies can reduce inequalities in health, for example, by targeting services to address the health disadvantages of those groups of people living in the most deprived areas
- Continue to roll out the HPV Immunisation Programme
- Improve public awareness about the risks of exposure to the sun through awareness-raising campaigns and the implementation of controls on the use of sunbeds
- Consider Health and Safety Executive advice expected in November 2009 on occupational links to cancer
- Support a comprehensive programme of cancer prevention research.



SECTION THREE:

EARLY DETECTION OF CANCER

3. EARLY DETECTION OF CANCER

The earlier a cancer is diagnosed, the better the chance there is of a complete cure. The Scottish Government is committed to an evidence-based approach to screening, based upon the advice of the UK National Screening Committee and supports national screening programmes for cervical, breast and bowel cancers. The Scottish National Advisory Group on Breast and Cervical screening (NAG) assesses emerging evidence from research and provides advice on possible changes to these programmes. Advice on bowel screening is provided by the Scottish Bowel Screening Programme Board.

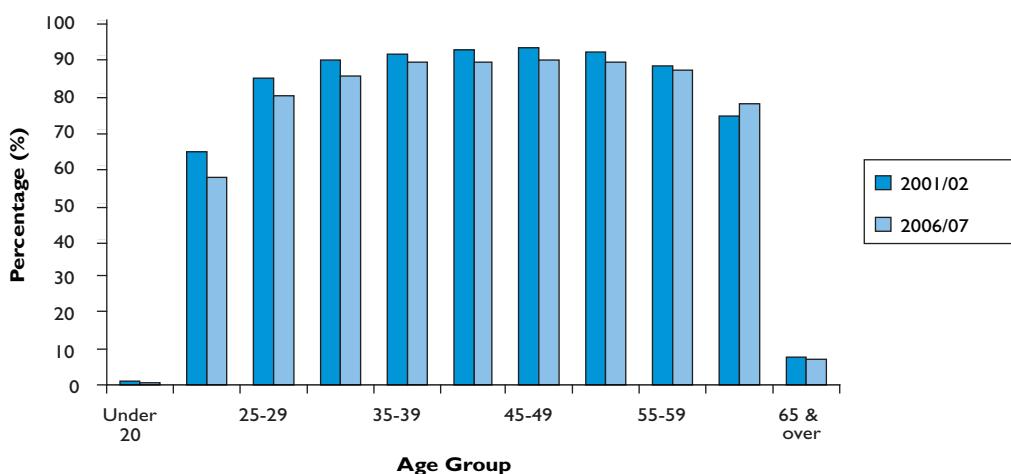
Scottish Cervical Screening Programme

The Scottish Cervical Screening Programme was introduced in 1988 with the aim of reducing the incidence of invasive cancer of the cervix. Cervical screening is offered to eligible women aged 20-60 every three years and women with an abnormal result are invited for follow up as appropriate. The incidence of cervical cancer decreased by 47.7% between 1986 and 2005. Just over 400,000 tests were completed during 2006/07, with 3.5% of tests showing an abnormal result.

The introduction of Liquid Based Cytology as the method for preparing samples for laboratory examination has helped to reduce the percentage of test results that are deemed unsatisfactory from 8.8% in 2003/04 to 2.4% in 2007. This has reduced the unnecessary anxiety associated with an unsatisfactory result and the need for women to have their test repeated. The Scottish Cervical Call/Recall System (SCCRS) was introduced in May 2007 to improve 'call/recall' arrangements. The purpose of this electronic system is to allow standardised call and recall, online updating of information and speedy reporting of results in line with the national *NHS Quality Improvement Scotland (NHS QIS) Standards for Cervical Screening*, which require 80% of women to receive results within four weeks of their test. The data generated by this system will enable the quality of the national programme to be assessed against NHS QIS standards and will allow NHS Boards to consider further action that might be necessary to meet these standards at a local level.

Over the past five years there has been a gradual fall in uptake for cervical screening especially in the 20-24 age group (Figure 8). As such, there is an urgent need to ensure that young women, whether they have been immunised or not, still attend for cervical screening. The publicity generated by the HPV Immunisation Programme will reinforce the importance of the screening programme.

Figure 8: Comparative uptake for cervical screening by age group – for 2001/02 and 2006/07



This graph shows the percentage of women who have attended for cervical screening within the last 5.5 years by age group. Excludes Lothian data, based on adjusted Community Health Index (excluding medically ineligible women).

Data Source: ISD

Example of Good Practice in Scotland

Community Health Educators: Addressing Cervical Screening Uptake Among Vulnerable Groups In Lanarkshire, Scotland

Women in the most deprived areas and from certain ethnic minority communities tend to be less likely to take part in cervical screening. NHS Lanarkshire is addressing cervical screening uptake among its vulnerable groups, by exploring factors affecting participation, using a combination of qualitative and quantitative techniques. The research exercise found that community health educators (trained 'lay' members of the community, who deliver education) have been successful in promoting awareness, knowledge and uptake in cervical screening in ethnic minority communities, making a potentially sensitive topic more accessible to these communities. There were clearly defined areas found which could be packaged into a resource to support professionals.

'Test of Cure'

'Test of cure' is a different follow-up pathway for managing patients who have been treated for high-grade cervical disease (CIN2+). There is evidence to suggest that the use of HPV testing, in conjunction with cytology, will identify at an early stage those who are likely to show residual or recurrent disease after treatment. This will reduce the number of cervical smears required in those women who are HPV negative and have cytology results within normal limits. A sub group of the NAG considered the implications of this evidence for the Scottish Cervical Screening Programme, concluding that the intervention should be further explored in terms of service and organisational impact, cost and the options for service delivery appraised. The Scottish Government has agreed to fund a project to take this work forward.

Use of Computer Technology to Assess Cervical Cytology Slides

Automated imager systems, a new technology currently being used in the USA, detects abnormal cells and directs the cytology screener to the appropriate fields of view on a slide, rather than the screener looking at all the fields of view. This technology may change the way that laboratory testing in Scotland is delivered for the cervical screening programme in the future. Its implications are being considered by a review group, established to provide advice on the future requirements of the Scottish Cervical Cytology Laboratory Service. As part of this process, a feasibility study has been commissioned on the use of an automated imager system for the Scottish Cervical Screening Programme.

Scottish Bowel Screening Programme

In 2005, colorectal cancer accounted for 14.5% of all cancer in men and 11.3% in women. There have been significant improvements in survival for cancers of the colon and the rectum. Around 55% of patients diagnosed between 2000 and 2004 are now surviving at least five years after diagnosis, compared to around 35% of those diagnosed between 1980 and 1984.

The Scottish arm of a UK colorectal cancer screening pilot commenced in April 2000 in NHS Tayside, NHS Fife and NHS Grampian and was completed in May 2007. Following a successful evaluation of the pilot, it was agreed to roll out a population-based bowel screening programme from June 2007 with the pilot NHS Boards implementing the screening programme first and other Scottish NHS Boards phasing it in over the next two years, up to December 2009. All men and women aged between 50 and 74 years are being invited to participate in the programme through completion of a faecal occult blood test (FOBt) at home every two years. Data from the three rounds of the pilot (2000-2007) are set out in Table 4. When implementation is complete, more than 700,000 people in Scotland will be issued with home test kits every year and it is estimated that the programme may prevent 150 premature deaths per year.

Table 4. Bowel screening pilot (men and women aged 50-69) summary data

	Round 1 Apr 2000 - Dec 2002	Round 2 Dec 2002 - Apr 2005	Round 3 May 2005 - Jun 2007
Number completing screening process	167,415	164,077	175,853
Number of positive results	3,464	3,123	2,044
% of positive results	2.1%	1.9%	1.2%
Number having colonoscopy	2,961	2,795	1,661
Numbers of cancers found	354	197	124
Cancers detected in those who tested FOBt positive	12%	7%	7%

Data Source: ISD

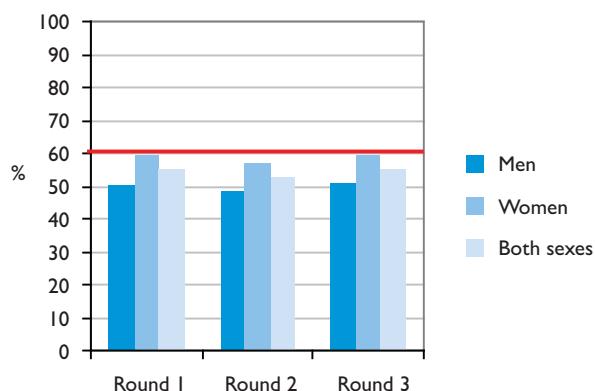
NHS QIS has published a range of standards relating to the Scottish Bowel Screening Programme. These include a national target for the Scottish Bowel Screening Programme that 60% of those invited to participate respond and complete a test.

“More needs to be done to make men go for this screening as they often wait until it is too late.”

Better Cancer Care Consultation Respondent

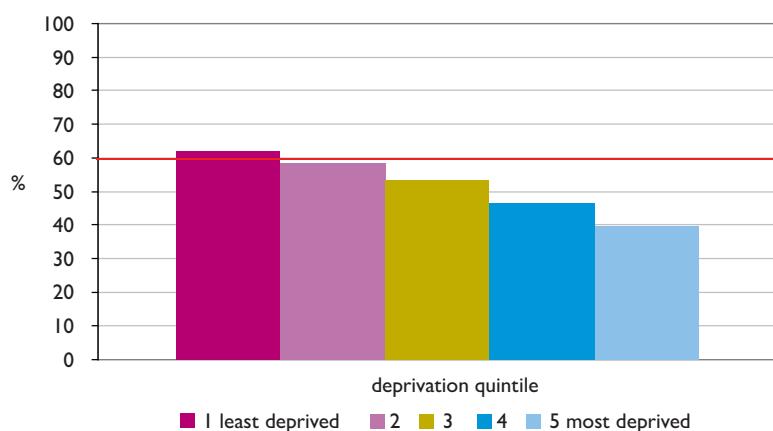
During the pilot phase, uptake stood at only 54.4% (Figure 9) so more needs to be done to encourage uptake. Uptake in men is particularly challenging being around 8-10% lower than that amongst women. Furthermore, a particular focus will be required in Scotland's less affluent communities, given that uptake in the least deprived quintile was 50% higher than in the most deprived quintile (Figure 10).

Figure 9: Percentage uptake of screening by gender and round



Data Source: ISD

Figure 10: Percentage uptake of screening by Scottish Index of Multiple Deprivation Quintile



Data Source: ISD

Scottish Breast Screening Programme

Breast screening in Scotland had its twentieth anniversary in 2008. Women aged 50-70 are invited for breast screening every three years by GP practice. Screening can also be requested by women over 70. In 2006/07 over 166,000 women of all ages were screened in the programme. Over 8,400 women were recalled for further investigations, leading to the diagnosis of 1,395 cases of cancer. Figures show that 76.5% of women aged 50-64 resident in Scotland have been screened at least once in the previous three years.

Currently, two x-ray views are taken at the first screening appointment and one view at all later screening appointments. This will change to two x-ray views being taken of each breast, but from different angles, at all appointments. Forecasts show that this will lead to an additional 275 cancers being detected through the screening programme. This change to appointments should be fully implemented across Scotland by April 2010 and £13.4 million has been set aside to achieve this. Work on pathways and role redesign, in order to support the implementation of two views, will be taken forward by the Scottish Government's Improvement and Support Team in partnership with Scottish Breast Screening Programme.

NHS QIS published a status report in December 2006 on the Scottish Breast Screening Programme and reported that “*the programme achieves high clinical standards, not as a one-off, but consistently, year after year*”. The report made five recommendations:

- Monitor and report performance of radiologists and other film readers
- Reduce the number of women recalled for assessment after their first screening appointment
- Meet the targets for issuing results
- Each Scottish Breast Screening service needs to assess and manage the risks associated with breast screening, so that they can assure the clinical governance committee of their host NHS Board that risks are minimised
- NHSScotland has to use the experience gained from breast screening to improve breast cancer services generally.

The Scottish Breast Screening Programme has been tasked with addressing these issues and to continue working with the Scottish Government and NHS Boards to ensure the appropriate level of staffing and training needs of the workforce are met. In addition, there may be a need to redesign services to better meet the needs of women attending the screening units.

The Scottish Breast Screening Programme is currently undertaking early planning for the introduction of digital mammography where digital images, rather than film images, will be used. Digital images have advantages over film records as they can be viewed, used and stored on a computer. Although this technology is unlikely to be introduced systematically before 2011, it offers the screening service far greater flexibility because images can be

read at a different location. A recent study compared the double reading of mammograms (i.e. two radiology consultants examining the mammogram films) with a single reading and a computer assisted programme; the results showed a similar performance in both groups. The NAG will be asked to look at these results and advise on the possible use of this technology in the Scottish Breast Screening Programme.

Tackling Inequalities

“Travelling communities have structured, family networks. To access the younger generations, the matriarch (grandmothers usually) need to be targeted.”

Better Cancer Care Fair for All – Ethnic Minorities Roadshow Participant

NHS Boards have a responsibility for ensuring the quality and performance of care for the patients within their Board area and also for encouraging uptake of screening in their local population. Screening services need to be accessible to all. This includes disabled people (whatever their impairment) and would, for example, include people with learning disabilities, amongst whom there are much lower rates of screening for cervical and breast cancer. It is also known that attendance at screening varies by gender, age and socio-economic group. Such issues are being addressed, for example, for bowel screening. It is the NHS Boards' responsibility to develop protocols for gypsies/travellers and homeless people, in line with the terms of the *Scottish Bowel Screening* manual.

A study conducted in NHS Greater Glasgow & Clyde found that the uptake of cervical screening by women with learning disabilities was markedly lower (at 13.5%) than for all women in this NHS Board area (74% overall). Some women with learning disabilities are more disadvantaged than others and the reasons for poor uptake are likely to be related to the multiple barriers to access experienced by this group. Marital status, living circumstances, pregnancy history, contraceptive usage, smoking and the level of learning disability were all significantly associated with uptake rate.

Example of Good Practice in Scotland

Breast Screening

To ensure that the service is as accessible as possible, mobile breast screening units are used for approximately 80% of appointments. These units can be parked in areas such as Community Centres and GP surgeries and are (manual) wheelchair accessible. The units are also used to ensure women in long-stay institutions, such as state hospitals, can access screening.

The Scottish Government is addressing the health inequalities that can be seen between Scotland's least deprived and most deprived communities through its support of the *Keep Well* programme. Aimed at 45-64 year olds in the 15% most deprived communities of Scotland, the programme engages with those who typically do not make full use of the health services available to them, inviting them to attend a health check at their local GP practice or a suitable alternative venue. Whilst this programme focuses in particular on assessing the risk of cardiovascular disease, there are similarities in terms of the risk factors for cancer and the *Keep Well* programme offers a unique opportunity to tackle cancer inequalities.

At present, it is difficult to identify differences in access to screening services amongst different ethnic groups because ethnicity is not routinely documented in medical records. It is planned to expand incentives to improve ethnicity recording in GP records through the General Medical Services contract in Scotland. A Chief Scientist Office-funded project is underway to study ethnic variation in health, health service utilisation and health outcomes in Scotland. This project uses record linkage between Scotland's health databases and the 2001 census data, creating a retrospective cohort study of about 5 million people. These findings will provide valuable data that NHSScotland can use to address the needs of ethnic minority groups, demonstrating compliance with legislation and NHS policy.

Screening for Prostate Cancer

The prostate specific antigen (PSA) test is one of a range of investigations which may be undertaken to confirm a diagnosis of prostate cancer. At present, the UK National Screening Committee recommends that a national screening programme for prostate cancer using the current PSA test would not be beneficial and could cause unnecessary harm because some men would be offered treatment they may not require. In addition, recent published evidence from the USA advises against PSA screening. Current PSA testing cannot differentiate between men whose prostate cancer will grow rapidly and aggressively and those in whom it will remain localised to the prostate for the rest of their lives. PSA levels may also be raised in a number of conditions unrelated to cancer.

Although there are no current plans for a national screening programme, the PSA test is readily accessible via GPs. Due to issues surrounding sensitivity and specificity, as well as those regarding treatment and possible side-effects (current treatments for prostate cancer can have serious side-effects, including impotence and incontinence), there is a requirement for GPs to fully explain all of these issues to enable men to make an informed choice before proceeding to have a PSA test. The UK National Screening Committee will continue to review all new evidence on this topic as it becomes available.

Screening for Lung Cancer

The Health Technology Assessment (HTA) programme has requested feasibility studies in lung cancer screening. The aim is to identify the potential cost effectiveness of a screening programme in high-risk individuals, probably using spiral computed technology (CT) imaging. Clearly there is considerable benefit to patients if lung cancer can be detected much earlier and at a point when surgery is a treatment option. If the early feasibility work is encouraging, it is expected that this will lead to a large trial run across the UK. Should such trials go ahead patients from across Scotland will be encouraged to participate.

We will:

- Provide advice through the National Advisory Group to NHS Boards on further national, regional and local actions that can be taken to increase the uptake of cervical screening services, particularly amongst younger women
- Carry out a programme of research and attitudinal surveys through NHS Health Scotland into the reasons for non-uptake of cervical cancer screening in order to inform this advice
- Fund a pilot for the 'test of cure' treatment pathway to determine how this programme may be integrated with the Scottish Cervical Screening Programme in both a clinically and cost effective way
- Take advantage of the opportunity provided by the HPV immunisation programme to reinforce messages about the continuing importance of cervical screening
- Consider and respond to the recommendations of the Cervical Cytology Laboratory Review Group on the future laboratory requirements of the cervical screening programme when it provides its advice in 2009
- Ensure that the Scottish Bowel Screening Programme is rolled out across Scotland by the end of 2009
- Consider actions that might be taken within primary care to improve uptake of the Scottish Bowel Screening Programme
- Look at means to encourage relevant individuals' participation in Scottish Bowel Screening Programme, for example, by exploring the use of *Keep Well* projects for inclusion of Scottish Bowel Screening Programme information
- Monitor compliance with the NHS QIS standards for the Scottish Bowel Screening Programme
- Implement two x-ray views at each breast screening round by April 2010. There may need to be redesign of roles and services to achieve this
- Support screening services to examine the processes involved in the breast screening pathway and explore opportunities for improvement
- Consider any developments in technology or screening tests that may improve the screening programmes
- Complete the Chief Scientist Office-funded study which seeks to address the information gap relating to ethnicity and medical recording
- Work with the Chief Scientist Office to examine opportunities to support Scottish researchers and patients participating in lung cancer research trials.



SECTION FOUR:

GENETIC AND MOLECULAR TESTING FOR CANCER

4. GENETIC AND MOLECULAR TESTING FOR CANCER

A small proportion of cancers is caused by inherited genes that predispose individuals carrying such genes to the development of malignant changes within their cells. Some inherited cancer predisposing genes result in rare forms of cancer such as retinoblastoma or multiple endocrine neoplasia. The proportion of more common cancers such as breast, colorectal or ovarian cancer caused by inherited genes is small, but the lifetime risks for those who have inherited the predisposing genes can be very high. Given that such inherited cancers often present in those who are younger than the age groups covered by national screening programmes, special arrangements are required for the identification, risk assessment and testing of such individuals.

“The field of genetic testing is about to explode in both its capacity and its ability to predict individuals at risk of cancer.”

Better Cancer Care Consultation Respondent

Cancer Genetic Services

Scotland now has a coordinated cancer genetic service which is run from four regional genetic centres in Edinburgh, Glasgow, Dundee and Aberdeen. Specialist genetic counsellors work alongside clinical geneticists to raise awareness and facilitate the identification of those at risk. They provide individual risk assessment and advice for those who are, and who fear they are, at risk. Their role includes the ‘triaging’ of referrals, so that primary care can more effectively act as guardians for the specialist secondary service. Those patients deemed to be at lower or moderate risk are therefore supported by genetic counsellors in collaboration with the primary care team, whilst those who are at higher risk are seen within the specialist cancer genetic clinic.

Selecting the appropriate test for an individual requires highly specialised knowledge of diagnostic options and access to information about the latest developments in the field. Interpretation of the results requires expert understanding of the correlation between clinical and molecular findings. A significant investment has been made in Scotland’s molecular genetic laboratories, to reduce the turnaround times for test results. The results for the full complex gene sequencing in, for example, the large genes associated with breast and large bowel cancer are now turned around within 40 days for the index case in a family (the first case to present in the family where the mutation is not known). This contrasts with response times of between one and three years in the past. The results of predictive tests on subsequent family members at risk, where the gene abnormality has already been identified, are usually available within ten days.

Scottish Molecular Genetics Consortium

The four molecular genetics laboratories in Scotland have, for some years, worked in a formal consortium arrangement as the Scottish Molecular Genetics Consortium, which is overseen by a steering group. The service is centrally commissioned and funded as a national service for Scotland. This arrangement has been highly successful and enables equity of access for all Scottish patients to a very comprehensive list of, often rare, molecular genetic tests. It also enables the retention of expertise for less common (or low

volume) tests whilst avoiding the wasteful duplication that would occur if rare tests were done in all centres. Patients are seen and counselled by their local genetics service and the deoxyribonucleic acid (DNA) is sent to the nominated laboratory within the Consortium which has responsibility for providing the relevant test. The model has enabled both specialisation and rationalisation of provision for some more common tests.

The tests offered by the molecular genetics service use analysis of DNA to detect a range of genetic disorders. An important and relatively new area is the diagnosis and prediction of inherited forms of cancer and genetic testing for inherited bowel and breast cancer has been incorporated within the service available in Scotland. Molecular genetics laboratories play an important role in providing diagnostic testing for patients with inherited forms of cancer. They also offer pre-symptomatic testing for the specific genetic disorder in other family members at risk and, where appropriate, pre-natal diagnosis. Increasingly, molecular genetic tests are being used for patient management in other ways, such as targeting particular treatments for patients with specific genetic changes.

The four Scottish laboratories are also members of, and play a full part in, the recently established UK Genetic Testing Network. Through this mechanism tests can be arranged for Scottish families in other UK laboratories and Scottish laboratory expertise is made available for patients outside Scotland who have rare genetic disorders.

Investment

Following the publication of the *Review of Genetics in Relation to Healthcare in Scotland* in 2006 (the 'Calman Review') significant additional funding has been provided to upgrade clinical and laboratory facilities and recruit more staff to a range of medical, clinical, scientific, nursing, administrative and psychological functions within the genetic services in Scotland. Further investment of over £2 million per annum is now planned in Scotland's genetic services. This will increase the number of consultant geneticists and genetic counsellors who liaise between primary care teams and the genetic clinics and who provide a resource for carrying out necessary risk assessments. It will also enable NHS Boards to recruit clinical psychologists to offer psychological support, where appropriate, to people undergoing genetic tests. This reflects the anxieties that can be caused by the process of testing, waiting for results and considering the implications of genetic results.

The Scottish Government is also working in conjunction with the University of Edinburgh on a public engagement network which will involve the establishment of a formal, funded network, to not only link together all those from a variety of backgrounds who have an interest in enhancing public engagement with genetics, but will also provide a means of bringing together all those in social science and the humanities around Scotland who are working in this area of research. Through this network, it is hoped that public awareness of the important role that genetics can play in cancer and its treatment will be increased.

Following the 'Calman Review', the decision was taken to extend the work of the Molecular Genetics Consortium to include cytogenetic services (the study of chromosomes and cell division). The networked approach proposed offers the potential for cytogenetics to play an increasingly important role in the diagnosis and treatment of cancer, with treatments becoming tailored dependent on a person's genetic and physiological make-up and help to monitor the response to treatment in some patients.

Education of Healthcare Professionals to Enhance Identification and Understanding

As the proportion of cancer patients in which genetic aspects are known to be important increases, it will not be possible for genetic services to deal with the problem alone. It is vital that other professional groups are equipped with appropriate genetic knowledge so that they may become further involved. The Scottish Government will continue to fund NHS Education for Scotland (NES) in their work with the Scottish Genetics Education Network and the Birmingham Genetics Education and Development Centre to enhance the genetic knowledge and skills of all healthcare professionals. This work will better equip those working in cancer services and primary care to be able to recognise the potential role of genetic factors in individual patients and offer appropriate advice and care.

To assist GPs and others to manage patients with a family history of cancer, guidance has been issued in Health Department Letter (HDL) HDL (2001) 24 *Cancer Genetics Services in Scotland: Guidance to Support the Implementation of Genetic Services for Breast, Ovarian and Colorectal Cancer Predisposition* and HDL (2007) 08, *Cancer Genetics Services in Scotland – Management of Women with a Family History of Breast Cancer*. Understanding familial cancer risk may also inform a person's ability to plan for the future and ultimately impact on their lifestyle and healthcare decisions, family planning, or other decisions.

Example of Good Practice in Scotland

The West of Scotland Primary Care Group has developed a guidance for referral into Genetics services leaflet. The leaflet will be disseminated across all Community Health Partnerships and GP practices in the West of Scotland and clearly outlines:

- where all referrals should be sent to
- the type of information that should be included in a referral
- what the service can offer
- what the genetics risks are for breast, ovarian and colorectal cancers
- how to deal with patients who wish to have blood stored for possible future testing.

Molecular Pathology

Molecular pathology is a scientific discipline that encompasses the development of molecular and genetic approaches to the diagnosis and classification of human tumours and will become the norm with major improvements in how diagnostic tissue is processed. There are two main areas where molecular pathology may have an impact on treatment and diagnostic services:

- Aiding diagnosis and classification of cancer
- Aiding assessment of treatment response and disease progression.

The role of molecular diagnostics must be integrated into routine practice and there is a need to examine how molecular pathology services are organised and provided across Scotland to ensure they are available to all cancer patients.

Tissue Collection

Access to tissue samples for research purposes is integral to understanding both tumour biology and the response to drug treatments. One of the ways to do this is to study the pathology of the tumour tissue and relate these findings to clinical and outcome data. Research capability should be embedded into the fabric of routine NHS cancer diagnosis and management in order to offer patients in Scotland the opportunity to contribute to research that will lead to future improvements in cancer prevention and care.

As part of the national audit for some cancers, mechanisms could be put in place that will enable patients to be asked whether they give their permission to donate some of their tissue for the purposes of research. There are, of course, many issues surrounding consent, storage and research and if these issues can be resolved, then the resultant population-based resource will facilitate research aimed at better understanding the differences between patient subgroups, disease causation and outcome correlates; ultimately leading to the potential for prevention and individualised treatments. A working group, to include patient representatives, will be convened to consider these issues further. It is important that Scottish tissue banks work to the same high standards as those required through licensing by the Human Tissue Authority.

We will:

- Invest in more genetic consultants, genetic counsellors, laboratory staff and appropriate psychological support to strengthen Cancer Genetic Services and meet recommendations made in the 'Calman Review' of Genetics
- Continue to support NHS Education for Scotland, Scottish Genetics Education Network and other stakeholders to enhance the genetic knowledge and skills of all healthcare professionals
- Update the protocols to identify the groups of high-risk individuals and stratify their risk and improve the organisation of the surveillance programme for those at high risk across Scotland
- Support the development of a public engagement network to raise awareness and understanding of the potential benefits of genetic services
- Explore the role of the molecular diagnostics models for achieving integration into routine practice
- Convene a short-life working group to advise the Scottish Government on the feasibility of national collection of tissue and consider, in conjunction with patients and other key stakeholders, the issues surrounding consent, storage, and access.



SECTION FIVE:

REFERRAL AND DIAGNOSIS

5. REFERRAL AND DIAGNOSIS

The key components of successful cancer management include:

- Recognising and reporting symptoms early
- Expertise in identifying patients who require prompt referral
- Rapid access to investigations and treatment.

This is underpinned by good inter-professional communication, a highly-trained workforce and excellent two-way communication between healthcare workers and patients/carers.

Recognising Symptoms

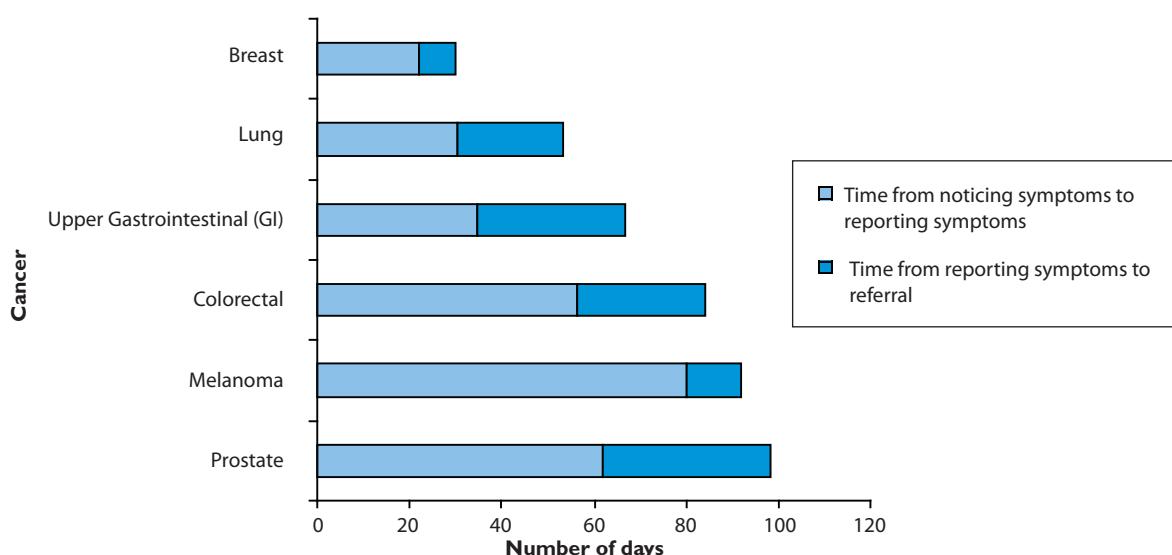
The cancer journey for many people starts when they notice symptoms. For others, however, even though survival rates and patient outcomes are improving and cancer is now very often a long-term condition, many people are reluctant to present, even when they have symptoms.

Evidence gathered from audits in primary care, as a result of nationally devised and locally-driven enhanced services for cancer care, indicates that patients frequently have symptoms for a considerable period of time before reporting them and seeking help (Figure 11). Findings from this audit must be acted upon to encourage people to see their GPs earlier to enable faster referral into diagnostic and treatment services. In order to achieve this, more work needs to be done with patients and their representatives to explore and further understand the issues that make them reluctant to come forward.

“A lot of men and women are terrified of going to a doctor to find out if they have cancer.”

Better Cancer Care Conference Workshop Participant

Figure 11: Time from patients noticing and reporting symptoms to GPs and time from patients reporting symptoms to GP referral to secondary care



Referral Process

HDL (2007) 09 Scottish Referral Guidelines for Suspected Cancer assists GPs and others to make an informed decision on their patients' conditions. While some people who are subsequently found to have cancer present with specific symptoms, such as a persistent lump, blood in sputum or a definite change in bowel habit, others present with much vaguer symptoms. It is important to remember that GPs will see many patients with signs and symptoms which, though similar, will turn out to be due to other common, benign ailments.

Timely referral from primary to secondary care is extremely important and best practice suggests that all such referrals should be submitted electronically. Electronic referral reduces the time taken for a referral to be received and acted upon. Some systems now depend entirely on electronic referral, but data from the 2005/2006 primary care-based cancer referral audit reported levels of electronic referral that varied from 14% to 51% of all urgent referrals. Whilst the use of electronic referral has improved significantly, scope for further improvement remains. Cancer networks and NHS Boards must consider how best to improve electronic referral rates, establishing systems in secondary and tertiary care services to triage all referrals (whether received electronically or by other means) in a more timely manner.

The use of specific cancer-related protocols was examined as part of the above audit and showed that a pro forma was used in only 24% of urgent referrals. While it is likely that this may also have improved over time, cancer networks and NHS Boards must consider the best use of appropriate templates to speed up the whole referral process.

Examples of Good Practice in Scotland

Redesign of Referral and Investigations Pathways Reducing Unnecessary Delays in: Lung Cancer

GPs can directly refer patients for a chest x-ray. In some NHS Boards where the radiologist reporting the x-ray suspects a diagnosis of lung cancer, a direct referral to the chest clinic to be seen by a respiratory physician or for a CT scan can be arranged with simultaneous notification to the patient's GP. This ensures rapid access to further investigations, diagnosis and treatment, thereby reducing waiting times.

Colorectal Cancer

In some NHS Boards, referrals for patients with symptoms suspicious of bowel cancer are triaged on receipt and if appropriate, patients are sent direct to test (colonoscopy or flexible sigmoidoscopy and barium enema). This reduces the number of clinic appointments a patient needs to attend and speeds the pathway to diagnosis.

Investigations

Where appropriate, and in keeping with best evidence guidelines, initial investigations should be conducted in primary care prior to referral unless a suspected diagnosis of cancer is evident. Where specialised investigations are required these should be offered in a timely way, that are sensitive to the patient's needs and provided as locally as possible.

Work undertaken by the Scottish Government Diagnostics Collaborative Programme has improved the availability of specialist investigations including those for suspected cancer. No patient should wait longer than nine weeks for CT, Magnetic Resonance Imaging (MRI), Ultrasound, Barium Enema, Upper and Lower Endoscopy and Cystoscopy, and this will inevitably benefit those eventually diagnosed with cancer.

All NHS Boards have effectively achieved the nine-week waiting times target for radiology and endoscopy services ahead of the target date of December 2007. This was due to the successful implementation of a variety of high-impact changes and improvements at local level, for example:

- NHS Forth Valley reduced the wait for CT scans from 12 weeks to six weeks by introducing extended day working
- NHS Lanarkshire introduced straight-to-test models, cutting unnecessary hospital visits and improving waiting times for outpatients and endoscopy
- NHS Greater Glasgow & Clyde introduced patient-focused booking for radiology and endoscopy services reducing patient Did Not Attend (DNA) rates to less than 5% and improving patient satisfaction.

As part of the 18 weeks referral to treatment programme, it is expected that any waiting times for these key tests will be minimised. As part of this strategy, NHS Boards are working towards a maximum wait of six weeks from March 2009.

Positron Emission Tomography

A relatively new diagnostic tool in cancer investigations is Positron Emission Tomography (PET), allied to CT (PET/CT). This is a form of scanning that depends on cancer cell function rather than solely assessing its size. It detects cancer cells that may not be picked up by other imaging technologies. After treatment such as chemotherapy, it may indicate whether a lump is simply scar tissue or active cancer.

After the announcement of an initial £5 million investment in 2004, the Scottish PET Advisory Group was formed to oversee the introduction of this service. Modern PET/CT scanners are now operational in Aberdeen and Glasgow. Edinburgh has the use of a mobile scanner, pending the completion of installation works for a permanent machine expected to be clinically operational in 2009. In 2008, the Scottish Government approved the business case for the installation of a PET/CT facility in Dundee.

PET is being developed as a Scotland-wide service with a single point of entry for appointments, to ensure that any patient needing a scan will receive it as soon as possible at whichever centre has the first available appointment. The clinical indications for PET scanning have grown rapidly in recent years. Clinical protocols based on best evidence for specific tumour types have been developed and are reviewed regularly by expert groups in Scotland.

All of these PET/CT facilities are being developed in close collaboration with relevant universities and medical schools. These facilities will greatly strengthen Scotland's ability to take forward ambitious research proposals nationally and internationally and will eventually be accompanied by a cyclotron to generate the isotopes (radioactive material) necessary for research as well as routine clinical use. A Scottish PET Research Group was established to ensure maximal advantage is taken of the opportunities currently available and to coordinate efforts with the PET Research Group of the UK's National Cancer Research Institute, which has published a PET Research Strategy.

We will:

- Work with the Scottish Primary Care Cancer Group, NHS Health Scotland, health promotion teams, voluntary groups, patients and others to assess how to improve public awareness of common cancer symptoms to encourage patients to present early
- Work with partners (including regional cancer networks, NHS Boards and the Scottish Primary Care Cancer Group) to audit levels of electronic referral and support NHS Boards to further increase such referrals in line with established best practice
- Improve the process of electronic referrals so that all such referrals include GP practice email addresses
- Establish live links between all local electronic systems and agreed local referral guidelines based on HDL (2007) 09 *Scottish Referral Guidelines for Suspected Cancer*
- Work with NHS Boards to explore the potential for the redesign of referral and investigations pathways, to reduce unnecessary delays
- Identify a designated primary care lead with responsibility for cancer within each NHS Board, with a remit that includes contributing to the development and evaluation of cancer services across the whole patient pathway and in particular, at the boundaries between primary and secondary care
- Continue nationally devised and locally driven enhanced services for cancer care in primary care. These should support improvements in direct cancer care and in cancer services development
- Continue to work to develop a collaborative which will organise Scotland-wide PET services
- Take advantage of future PET/CT research opportunities in Scotland and elsewhere.



SECTION SIX:

TREATMENT

6. TREATMENT

There are many different types of cancer, each with its own particular behaviour. Cancer treatment can involve surgery, radiotherapy, chemotherapy (includes drug therapy, hormone therapy and other agents) or often all three, with the choice of therapy depending on the location and natural history of the particular tumour type. Treatment can be curative for many patients, whilst in others, it may offer a partial cure or palliation of symptoms.

Figure 12: Different types of treatment for patients with cancer in Scotland in 2001 and 2005

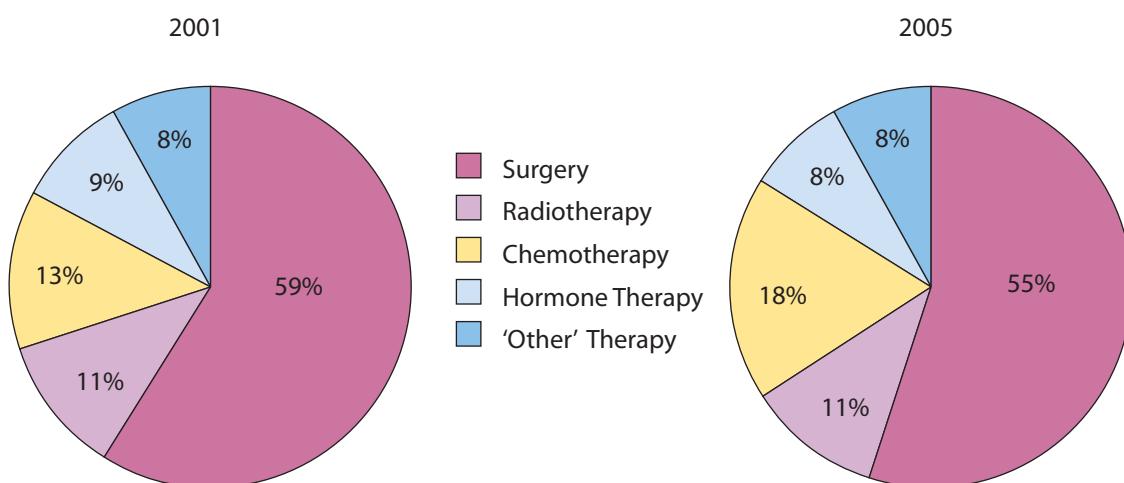


Figure 12 refers only to patients receiving treatment within six months of diagnosis, and primary (first time) cases only. This does not reflect the ultimate utilisation of any particular treatment in the course of an illness.

Data Source: ISD

Decisions about the appropriate treatment for each patient are made following a multi-disciplinary team (MDT) meeting and in discussion with patients and carers. It is important that primary care teams are aware of these discussions and conclusions as soon as practical to enable them to answer questions that patients may have and help to ensure a seamless service for patients.

Surgery

Surgery remains one of the most important treatments for cancer, for example, in the period of 2001-2005 (Table 5) nearly 80% of patients diagnosed with breast cancer underwent surgery in the first six months after diagnosis.

Table 5: Surgery rates^a for patients diagnosed with cancer^b in the period 2001-2005, Scotland

Cancer type	Number of cancer registrations	Number undergoing surgery	% of tumour type undergoing surgery
Head and Neck	5,090	2,695	52.9
Oesophagus	4,115	944	22.9
Stomach	4,281	1,368	32.0
Colorectal	17,341	13,027	75.1
Trachea, bronchus and lung	22,979	2,454	10.7
Breast	19,241	15,341	79.7
Ovary	3,106	1,967	63.3
Prostate	12,266	2,766	22.6
Other malignant neoplasms	45,272	17,813	39.9
All malignant neoplasms	133,691	58,375	43.7

^a Analysis restricted to treatment in the period covering the first six months after diagnosis

^b All malignant neoplasms excluding non-melanoma skin cancer

Data Source: ISD

Many patients are admitted to hospitals as emergencies and are then diagnosed with cancer during the course of their admission. It is therefore important that surgical services are available locally wherever possible and that patient outcomes are comparable across Scotland.

Surgical Audit

Many tumour-specific clinical networks have progressed local, regional and national audits that highlight areas of relative strengths and weaknesses. Such approaches enable services to take action to improve performance and should be encouraged across all tumour-specific networks. National indicators of quality and national audit data will be collected as part of a work programme to improve the quality of cancer services. This will enable

services to be benchmarked at regional level and allow NHS Boards to examine their local data to ensure that the treatment provided is of the highest standard. This includes not only the surgery itself, but both pre-operative and post-operative care, infection control and paying close attention to patient safety issues. Therefore, it is important that processes as well as the outcomes are scrutinised. There will be further discussion relating to quality and the need for audit in other treatments in the *Improving Quality for Cancer Care for Patients* section.

Capacity and Demand Planning

As surgery is such an important treatment for cancer, NHS Boards need to work in collaboration with the three regional cancer networks to ensure that there are the right facilities, in the right places to meet the demand for surgical care. *Cancer Scenarios* examines the projected growth in each tumour type and it may aid planners in understanding how the demand will change in the coming years. This will allow the capacity to be put in place to cope with future demand.

Laparoscopic Colorectal Surgery

The National Institute for Health and Clinical Excellence (NICE) issued guidance in 2006 which recommended laparoscopic surgery as an alternative to open colorectal surgery, as there is evidence that clinical outcomes improve as a result. Key to the safe performance of the technique is optimal training and the Scottish Association of Medical Directors is carrying out a local needs assessment that can then inform decisions about how best to deliver and ensure consistent training throughout Scotland and assess the outcomes achieved from this technique.

Sentinel Node Biopsy in Breast Cancer

Sentinel Node Biopsy is a surgical technique used to identify the axillary node most likely to contain a tumour, so that only nodes with possible tumour involvement need to be removed at the time of staging surgery. Sentinel Node Biopsy replaces axillary lymph node clearance, or sampling, avoids the significant morbidity, reduces operative and theatre time, and also decreases hospital stay; indeed, some women now undergo surgery as a day case. Considerable progress has been made in introducing this technique across NHSScotland and many patients have already benefited from its use. Further development and training is required to complete implementation in all Scottish breast units surgically managing breast cancer. The Regional Cancer Advisory Groups (RCAGs), together with NHS Boards, will explore the feasibility of Sentinel Node Biopsy being made available across Scotland.

Chemotherapy and Drug Treatments

Chemotherapy is the use of medicines to destroy cells, including cancer cells. It includes cytotoxic ('cell-killing') drugs as well as hormonal and other biological medicines. The role of chemotherapy has expanded greatly since it was first used in the 1960s.

Chemotherapy might now be used as the sole treatment, as initial treatment prior to surgery or radiotherapy ('neo-adjuvant' treatment), following these treatments ('adjuvant' treatment) or be reserved until recurrence or spread of the cancer beyond the scope of further local treatment.

Treatment with chemotherapy carries the risk of short-term and long-term side-effects. Complex treatment requires highly-skilled staff to deliver doses of medication (often in combination) usually tailored specifically for each patient. Every effort is made through careful planning of treatment arrangements to minimise unpleasant side-effects. Side-effects from chemotherapy need to be balanced against the benefits that the treatment aims to achieve.

The most important opportunity to make a major impact on the behaviour of a newly diagnosed cancer lies with the first treatments offered. Regional and national tumour-specific Managed Clinical Networks (MCNs) have developed clinical management guidelines and protocols, including the most effective use of any Scottish Medicines Consortium-approved medicines, for each cancer type. Prospective evaluation of the use of second-line and subsequent chemotherapy should be coordinated. The development of controlled trials to assess the anti-tumour effectiveness, impact on quality of life and costs (personal and financial) of these treatments is to be encouraged, as the benefits of subsequent treatments are sometimes much less clear and need to be carefully audited.

Cytotoxic medicines also pose a risk to the staff who handle them, and measures are in place to minimise exposure. All chemotherapy services in Scotland must meet the stringent safety and quality standards set out in HDL (2005) 29 *Guidance for the Safe Use of Cytotoxic Chemotherapy*. All RCAGs and NHS Boards have either recently or are currently reviewing their chemotherapy services against the criteria in the HDL as well as the locations where chemotherapy can be safely delivered. In the light of concerns in England about the safe use of oral chemotherapy, quality standards in Scotland were reviewed in June 2008. This demonstrated that the issues raised are fully covered by the existing standards and will next be reviewed in 2011.

Example of Good Practice in Scotland

Over the last three years, clinical staff in NHS Orkney and the Aberdeen Cancer Centre collaborated to deliver more services and treatments in local communities. The outcome of this service development has been that NHS Orkney moved from administering very little chemotherapy prior to 2003, to over 140 treatments per annum in 2004, to 240 treatments in 2006.

Whilst it is recognised that not all chemotherapy can be given outside of cancer centres, it is possible to provide safe services closer to the patient's home for many chemotherapy regimens, where this is delivered within a shared care framework.

The experience in NHS Orkney is that success is dependent on the following:

- Developing relationships and collaborative working
- Defining responsibilities through shared care agreements
- Implementing local and regional protocols
- Supporting the services with telemedicine and other eHealth tools.

The benefits for patients receiving some of their chemotherapy in Orkney are:

- It greatly reduces the travel burden and time away from home for patients
- Patients are more satisfied
- It is safer (when given in a structured system) as local staff are more aware of potential problems and have the appropriate training to respond as necessary
- It reduces travel costs and inpatient admissions, helping to address capacity issues in the cancer centre.

“During the course of the patient journey, often there is no contact out of hours with the GP and a lack of liaison between branches. The hospital may not always be aware of the drug/treatment that the patient is on.”

Communication between primary and secondary care has to be improved.”

Better Cancer Care WoSCAN Roadshow Participant

Work is continuing to determine the best ways to ensure that all involved (patients, carers, primary care services and out-of-hours (OOH) services) are fully and rapidly aware of the nature of the chemotherapy that a patient has received, potential side-effects and their appropriate management at any time of day or night. Some cancer centres already use a form of patient-held record for this purpose which might be utilised nationally. Other possibilities to be explored include electronic communication between chemotherapy services, GP practices, OOH services and NHS 24. This work will be taken forward by the Scottish Chemotherapy Advisory Group.

As more treatments have become available, the amount of chemotherapy delivered to patients in Scotland has increased dramatically over recent years (Figures 13 and 14).

Figure 13: Increase in chemotherapy activity for the Beatson West of Scotland Cancer Centre 1999-2007

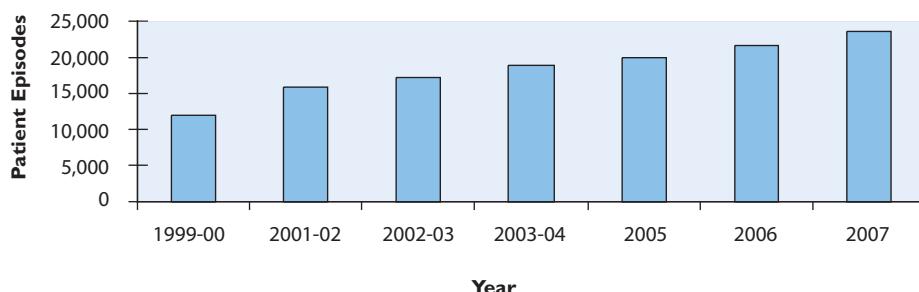
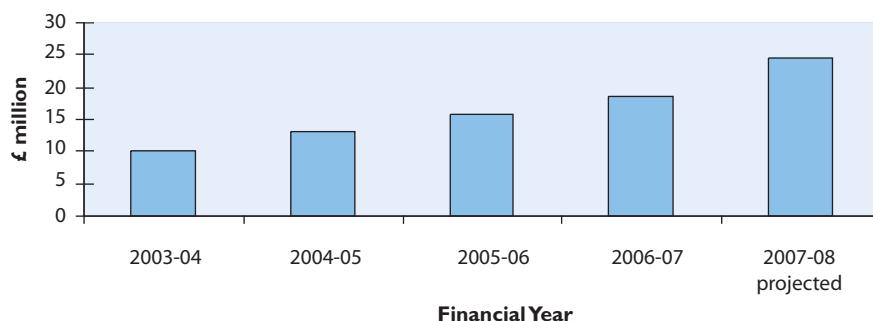


Figure 14: Financial increase in spend on cancer chemotherapy and biological therapies for the West of Scotland Cancer Network



Good information is important in the planning and provision of NHS services, facilitating the modernisation of pharmaceutical and clinical care and maximising access to chemotherapy. Safe delivery of chemotherapy needs to be supported by information technology (IT) systems, which will include an appropriately specified electronic prescribing and administration system (known as CEPAS). A preferred supplier of such a system for NHSScotland has been identified and contract negotiations are underway (at time of publication).

With an increasing number of patients receiving chemotherapy, capacity planning has also become a priority for chemotherapy services, and modelling tools, such as C-Port, have been developed to support this. The Scottish Government is supporting a one-year evaluation of C-Port both for improving current services and planning for the incorporation of new treatments and regimens in the future.

New Cancer Medicines

The Scottish Government is committed to ensuring the speedy implementation of effective new medicines and treatments in Scotland, and that implementation is achieved on an equitable basis. New treatments are often heralded as a 'cure', which can raise the expectations of patients and their families before evidence of the real benefits are available. Early research findings take several years to evaluate and may fail to translate into actual and effective treatment at an affordable cost. In Scotland, clinical and cost effectiveness of new drugs is assessed by the Scottish Medicines Consortium. A distinctive feature of the Scottish process is that the NHS has information on the clinical and cost effectiveness of a product at an early stage after the drug receives a marketing authorisation. This minimises the uncertainty on the part of NHSScotland and patients as to whether a medicine is approved for use or not.

NICE undertakes appraisals of groups of medicines (termed Multiple Technology Appraisals) on behalf of the Department of Health and the Welsh Assembly. If endorsed by NHS QIS, NHSScotland will adopt these recommendations as these appraisals consider a range of treatments (including drugs) against a more comprehensive evidence base (such as clinical trials) than is possible at the time of licensing. The remit and status of the output of the Scottish Medicines Consortium and its working relationship with NHS QIS is available on the following website:

www.nhshealthquality.org/nhsqis/files/22512NHSQISNICEAdvice.pdf

The Scottish Medicines Consortium horizon scanning initiative aims to prepare NHSScotland for the availability of new medicines. This supports NHS Boards with their financial planning and facilitates early patient access to those new medicines that Scottish Medicines Consortium later advises to be clinically and cost effective. As treatments become available for cancers with previously limited treatment options, the need for advance warning becomes increasingly important. The application of models, such as C-Port will assist in evaluating the service impact of new treatments.

The future challenge is to achieve transparency in these processes to allow a better understanding of these systems. This includes the work of the exceptional panels that consider appeals against decisions by NHS Boards, and reassure patients and their families that those with cancer are receiving the most appropriate treatment for their specific circumstances. In 2008, the Scottish Parliament Petitions Committee conducted an inquiry into the availability of cancer drugs in Scotland. The Scottish Government's response to the Committee's recommendations is available from:

www.scottish.parliament.uk/s3/committees/petitions/inquiries/cancerDrugs/ScottishGovernmentResponse.pdf

Sustained national and international research efforts over many years have meant that the number of new medicines and classes of medicines coming forward for marketing authorisation is now greater than ever. The European Medicines Agency Annual Report for 2007 highlights cancer treatments as the most represented therapeutic area for marketing authorisation application for new medicines; 16 of the 56 applications were for cancer medicines.

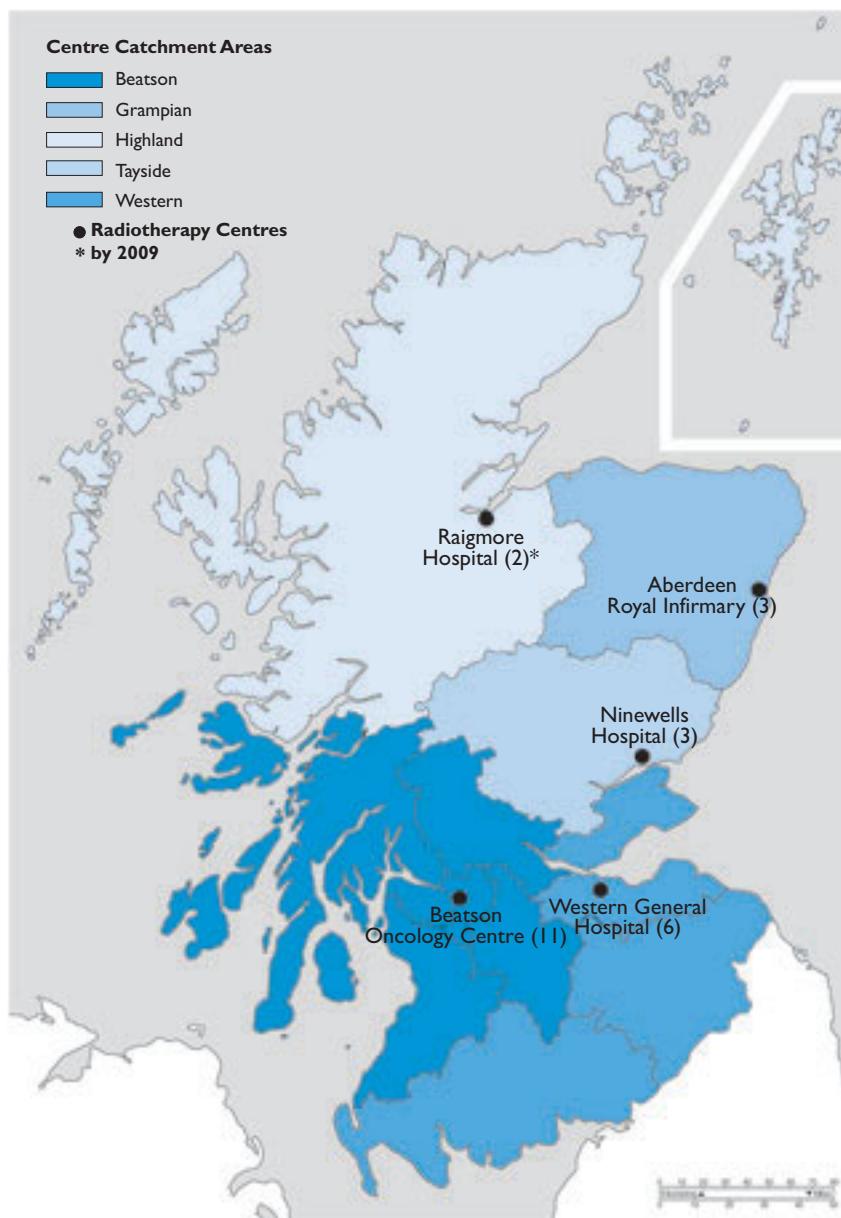
Radiotherapy

The report, *Radiotherapy Activity Planning 2011-2015* reaffirmed that radiotherapy is a key component of modern cancer treatment and will remain so for the foreseeable future. It may be given as the sole curative treatment (for example, cancer of the larynx) or as part of a treatment plan also incorporating surgery and chemotherapy. It also has an important role in the palliation of many symptoms. Approximately half of all cancer patients will require radiotherapy at some point in their treatment.

Radiotherapy is a technically demanding treatment requiring the combined efforts of skilled physics, radiography, nursing and medical staff. Quality in radiotherapy departments is subject to International Organisation for Standardisation (ISO)/The British Standards Institution (BSI) accreditation, and safety of staff, patients and the environment is subject to legislation which is regulated by the Health and Safety Executive, the Scottish Ministers and the Scottish Environment Protection Agency.

Inspections of all Scottish radiotherapy facilities have been undertaken, on behalf of the Scottish Ministers, to assess levels of compliance with the *Ionising Radiation (Medical Exposures) Regulations IR(ME)R* and associated guidance on good practice. As a result of these inspections, coordinated efforts are being made by all centres to achieve full regulatory compliance, with clear identification of the related roles and responsibilities.

All Scottish radiotherapy departments have modern equipment capable of delivering technically complex treatment. There is a long-term planned programme of replacement to ensure continuing efficiency. Scotland has one linear accelerator (the machines that delivery radiotherapy) per 204,000 of its population, with 25 in total:

Table 6: Number of linear accelerators per cancer centre catchment area

In addition to the predicted substantial rise in demand for radiotherapy, the complexity of planning and treatment is also likely to rise as the role of newer techniques such as Intensity Modulated Radiotherapy (IMRT) and Image Guided Radiotherapy (IGRT) becomes more clearly defined and incorporated into standard practice. Other techniques, such as stereotactic intracranial radiotherapy will also increase in use.

These developments will have significant implications for workforce planning and development. There are currently significant shortages in radiotherapy physics staff, and further actions beyond the increase in training posts already in place following the recommendations of the *Radiotherapy Activity Planning for Scotland 2011-2015* report are required. The expansion of IMRT and IGRT, in particular, is dependent on sufficient physics expertise. There is a need, therefore, to explore further cooperation and collaboration at a national level between the five radiotherapy physics departments, particularly for complex radiotherapy treatment planning.

The Scottish Radiotherapy Advisory Group (SRAG) is reviewing the *Radiotherapy Activity Planning for Scotland 2011-2015* report to determine the continuing accuracy of the assumptions that underpinned it and to update the capacity estimates required for the future. It is likely this work will be repeated every three to four years and will form a major part of the work plan for the SRAG. The current update is expected in early 2009.

The *Radiotherapy Activity Planning for Scotland 2011-2015* report considered the extension of the working day as a way of providing some of the increased capacity that may be needed, however, a combination of issues (such as staff shortages) has made this difficult to implement in all areas. Any additional capacity indentified by the review of the report is likely to require additional machines and workforce. The possibility of one or more small 'satellite' centre(s) (a centre on the site of a District General Hospital) should be explored as they might allow some treatment to be delivered closer to patients' homes.

The Technical Specification and Evaluation subgroup of the SRAG has proven an extremely effective forum for ensuring the timely replacement and efficient procurement of the stock of treatment machines across the cancer centres and ensuring that all have the equipment to deliver modern radiotherapy safely and the Group should continue with this role.

The complex nature of radiotherapy means that the five cancer centres providing treatment cooperate in the provision of some treatments that may only be required infrequently. Not all centres can or should provide all treatments, and provision of highly-specific treatments needed by a small number of patients should be considered by the SRAG, with a view to ensuring the most appropriate provision and referral pathways for patients wherever they live. Similarly, robust arrangements need to be in place for contingency planning to ensure continuity of treatment in the event of protracted machine failure or staff sickness. Contingency agreements were reached by all centres, brokered by the SRAG, to provide mutual support for all radiotherapy centres.

Research continues to be an important role for many clinicians and centres. Participation in radiotherapy trials with national research groups, such as the National Cancer Research Network (NCRN) and Academic Clinical Oncology and Radiobiology Research Network (ACORRN), and with international groups, such as the European Organisation for the Research and Treatment of Cancer (EORTC), will continue to be encouraged. It is recognised however, that due to increased quality assurance implications, participation is demanding of all staff groups. The Chief Scientist Office will therefore fund additional quality assurance support where this is an issue for participation in National Cancer Research Network trials.

New Techniques

There are few clear mechanisms for horizon scanning new techniques and technologies which may be used for either diagnosis or treatment. Some of these are in early stages of development, whilst others are already set to move into mainstream practice. This means that their introduction can be irregular with no coherent assessment of effectiveness once they have been adopted. There are essentially five steps in the life of a technology:

1. Innovation and Research and Development – require horizon scanning
2. Adoption pre-requisite – Health Technology Assessment (HTA), as a necessary first step
3. Ongoing assessment – proper audit and evaluation
4. Optimal utilisation – outcomes
5. Obsolescence – managing out of mainstream.

NICE reviews and issues Interventional Procedures Programme guidance (which is applicable in Scotland) on whether a technique is safe and efficacious. These recommendations vary depending on the quality of the evidence available and a health technology assessment is still required to consider the cost and effectiveness of each procedure. A national approach will ensure that such guidance is implemented and monitored in a coordinated and safe way. This will be supported by the Scottish Health Technologies Group, NHS Boards, NHS QIS and the RCAGs.

Expenditure on Cancer Research

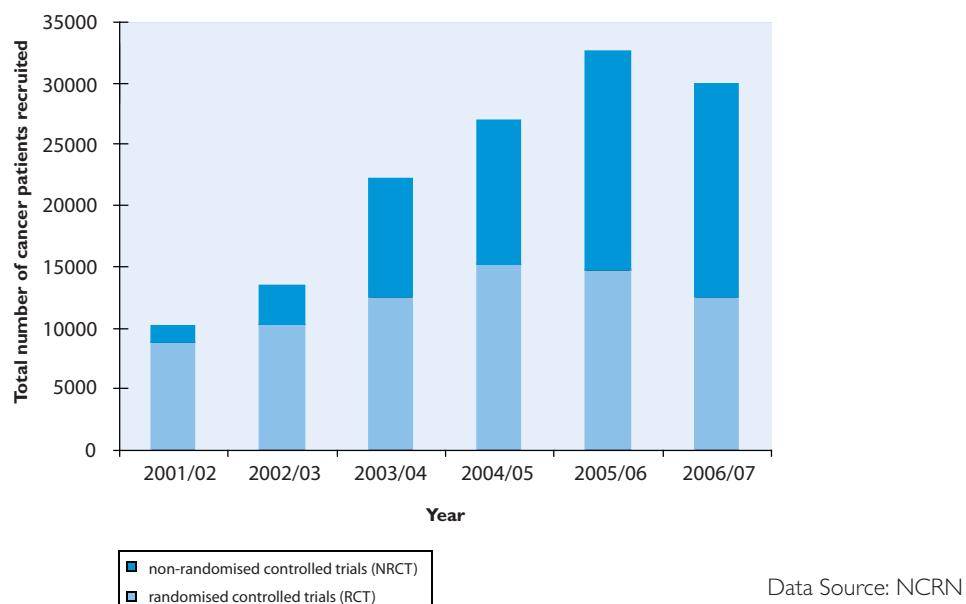
Each year the Scottish Government, through the Chief Scientist Office spends about £2.9 million on directly-funded research projects and initiatives as well as £10 million to support cancer research within NHSScotland. When cancer research financially supported by all funders is considered, Scottish researchers are highly successful and are granted 13.5% of UK expenditure – £392.7 million in 2006. Patient benefit is at the heart of this investment in cancer research, particularly through large intervention trials. These trials are not restricted to new drugs but include screening, diagnostics, therapies, surgery and newer treatment options. The aim is to integrate research into routine care and improve patient care by speeding up access to the best care and treatments across the country.

Example of Best Practice in Scotland

Cancer research has led the way in the UK Clinical Research Collaborative, with the creation of a Scottish Cancer Research Network in 2002. One of the network's initial targets was to double trial recruitment over a three-year period from a baseline of 3.7% of cancer patients. Recruitment rates have risen each year and reached 13.9% in 2005/06. A further aim of Scottish Cancer Research Network was to facilitate patients outwith the main cancer centres to participate in clinical trials and in 2005/06 this target was exceeded with 28% of these patients being recruited to trials. Indeed, this was a specific goal of the West of Scotland Cancer Research Network which recruited over 50% of its patients from outwith the main West of Scotland Oncology Centre.

Recruitment into trials fell quite significantly in 2006/07. There are a number of different factors that may have contributed to this, including increased European regulations, since similar falls were observed across the whole of the UK National Cancer Research Network (Figure 15).

Figure 15: Annual accrual to National Cancer Research Network Studies (UK)



The Scottish Cancer Research Network is bidding for extra funding (at time of publication) from the Chief Scientist Office for 2009-2012, at which time specific new targets for increased recruitment of patients to trials will be agreed to ensure recruitment exceeds the level of 13.9% achieved in 2005/06. These are likely to include:

- A greater focus on key, UK flagship trials, carried out across Scotland in the common tumour types; for example, breast, colorectal and lung
- A specific focus to increase recruitment in under-recruited groups, for example, lung, prostate, head and neck
- Conducting work to test whether electronic datasets available through ISD can be used to reliably capture long-term follow-up data.

Experimental Cancer Medicine

The Scottish Government has invested in translational cancer research. This is an exciting initiative, aimed at bringing together laboratory and clinical patient-based research to speed up the development of new treatments through Experimental Cancer Medicine Centres. Both Edinburgh and Glasgow Cancer Centres have been awarded Experimental Cancer Medicine Centre status. The total funding to each centre has increased with government funding matched by Cancer Research UK (total investment of £3.5 million over five years).

Translational research is now an integral part of early clinical trials in order to optimise the therapy being developed. This research is also essential in late clinical trials in order to define different patient populations that may benefit to differing degrees from new treatments. Support of translational research is therefore essential for clinical practice to move towards more personalised medicine.

Early achievements from the centres include the collection in Glasgow of samples of tumour and blood to form a repository of over 1,000 cases. These are being used in studies of drug resistance, in the development of novel biomarkers and should add to the efforts of other centres to develop individualised therapies. Edinburgh has developed an annotated tumour collection of patients treated with platinum drugs (500 patients) and the technology to use ribonucleic acid (RNA) from this archival material to conduct biomarker studies. There is also considerable scope for molecular imaging to facilitate such translational cancer research and this can be exploited through investment in PET/CT scanners for service provision.

We will:

- Support the continued development of regional and national audits to drive performance improvements
- Set out the best available information on future capacity and demand plans for surgery to support NHS Boards in service, financial and workforce planning
- Ensure NHS Boards undertake a needs assessment for laparoscopic colorectal surgery and support the development of a Scottish surgical network around this procedure
- Together with the RCAGs and NHS Boards, we will explore the feasibility of Sentinel Node Biopsy being made available across NHSScotland
- Work with patients, carers and other stakeholders to improve the transparency and accessibility to patients of the arrangements for introducing new drugs into the NHS in Scotland
- Support regional and national tumour-specific MCNs with the ongoing development of clinical management guidelines and protocols, including the most effective use of any Scottish Medicines Consortium-approved medicines
- Coordinate detailed prospective evaluation of the use of second-line and subsequent chemotherapy, and encourage the development of controlled trials to assess the effectiveness, impact on quality of life and costs (personal and financial) of these treatments.

We will:

- Evaluate and, if appropriate, support the widespread adoption of C-Port and CEPAS as a modelling tool for future service delivery
- Review chemotherapy safety and quality standards in 2011 and keep a watching brief on any new issues that may arise before then
- Encourage engagement and involvement in experimental cancer medicine to facilitate the evaluation and introduction of new cancer medicines for patients
- Support Scotland's five radiotherapy centres to enable a coordinated approach to contingency planning, workforce planning and horizon scanning
- Consider opportunities to meet the future demands identified from the review of *The Radiotherapy Activity Planning 2011-2015*, including the possibility of satellite centre(s)
- Explore further the potential of the five radiotherapy physics departments working in coordinated and collaborative ways, particularly for complex radiotherapy treatment planning
- Work with NHS Boards and other stakeholders to further develop improved mechanisms for the assessment and introduction of new techniques and technologies
- Set new targets to support increased recruitment of patients to trials, to ensure recruitment continues to exceed 13.9%.



SECTION SEVEN:

LIVING WITH CANCER

7. LIVING WITH CANCER

As Scotland's population ages, treatments advance and screening programmes prove increasingly effective at detecting cancers at an earlier stage, many more people will find themselves living with and beyond cancer. Patients and those who care for them face considerable uncertainty and may need to cope with unpleasant and sometimes debilitating treatments which could have both physical and psychological consequences for many years to come. They may receive treatment over many years as their condition relapses or remits. As a result, cancer is increasingly being seen as a long-term condition and healthcare providers, in both the statutory or voluntary sector, need to find ways of supporting and empowering patients, giving them the confidence and tools to enable them to maintain the level of independence they wish to have.

Survivorship

“After the original operation and the radiotherapy came the ‘that’s fine we will see you in a year’ period where I was left to get on with coming to terms with the fact that I had a cancerous brain tumour. After the superb care at the start of my journey I found a severe lack of after-care.”

“Many survivors of childhood cancer will experience social, emotional, physical and medical challenges long after their treatment is finished.”

Better Cancer Care Consultation Respondents

Macmillan Cancer Support define the concept of survivorship as, “... someone who has completed initial cancer management and has no apparent evidence of active disease, or is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six months of life), or has had cancer in the past”. Such survivors, they point out, have a range of physical, emotional, practical and financial needs.

The Scottish Government agrees that survivorship is far more than just a health issue and given that there is a lack of current data and research, further work is needed to fully understand survivorship needs. It will therefore establish a working group on survivorship, which will feed back to the Scottish Cancer Taskforce (as part of the new arrangements for overseeing the implementation of Better Cancer Care), to consider how best to maintain the focus on this issue and support NHSScotland and its partners in meeting survivorship needs. This will link to work that is taking place on such issues in UK-wide clinical studies development groups within the National Cancer Research Network in order to improve understanding of the issues involved and highlight any areas requiring further research.

Cancer Poverty

“The second greatest cause of stress among cancer patients, after diagnosis, is loss of income and resultant poverty.”

Better Cancer Care Consultation Respondent

Many people affected by cancer in Scotland experience significant levels of financial hardship as a direct result of their cancer diagnosis. Ninety per cent of people affected by cancer in the UK experience a drop in income and an increase in daily living expenditure because of their cancer diagnosis. As a result, many patients and families affected by a cancer diagnosis require financial advice and support on a wide range of issues including employment rights, debt, saving and borrowing, pension rights, fuel poverty and insurance.

The Scottish Government and Convention of Scottish Local Authorities will publish their joint *Framework to Tackle Poverty in Scotland* in November 2008. On the basis of the best available evidence, the Framework will set out a number of actions the Scottish Government and its partners will take to deliver improvement across four main areas:

- Reducing income inequalities
- Introducing longer-term measures to tackle poverty and the drivers of low income
- Supporting those experiencing poverty
- Making the tax and benefits system work for Scotland.

Good progress has already been made in partnership between the voluntary and public sectors in supporting people to navigate the benefits system and the new Framework will continue the process of developing financial inclusion activity across the public services in line with the recommendations of *Equally Well*. The need for further action to support people to meet the forward challenges they face in living with and beyond cancer was raised by a number of participants in the national discussion that informed the plan. The work of Macmillan Cancer Support and its partners in this field has made a valuable contribution to the lives of many people with cancer and the Scottish Government will invest £500,000 to help ensure the continuing expansion and success of this work. This will, amongst other things, allow for the development of new approaches to the delivery of financial advice and support to cancer patients and their families, including those living in remote and rural communities. The investment will also enhance the training that is available to help Welfare Rights officers, money advisors and other support staff in the voluntary and statutory sectors to better understand the issues of dealing with progressive illnesses, loss and bereavement, employability and disability discrimination. NHSScotland has an important role to play in ensuring all cancer patients who need it will be referred to benefits advisors as part of their routine care and the Scottish Cancer Taskforce and a working group on survivorship will be tasked with making this a reality.

Returning to Work

People of working age with a cancer diagnosis are six times more likely to report being unable to return to work compared with people with other illnesses because of their health. The new funding will also support a specific pilot programme to better understand the barriers to work faced by people with cancer and test opportunities for supporting people with cancer back into work and helping them to sustain that employment wherever possible. The Scottish Centre for Healthy Working Lives, part of NHS Health

Scotland will bring a national perspective to this work and will be tasked specifically with ensuring that the lessons learned are used to inform the development of similar initiatives across Scotland.

Tackling the Costs

The Scottish Government's commitment to abolishing prescription charges for all by 2011 has been welcomed by patients across Scotland but it recognises that this is only part of the picture. The *Cancer Costs* study by Macmillan Cancer Support showed that Scottish cancer patients face the highest costs in the UK for travelling to hospital for treatment, spending an average of £636 on travel and parking throughout the course of their cancer treatment. Whilst some of this disparity is an inevitable consequence of geography, the Scottish Government is committed to reducing the financial burden on cancer patients and has announced that hospital car parking charges at all NHS hospitals (except the three sites developed under Private Finance Initiative (PFI) arrangements) will end from 31 December 2008. This applies to all car parking provision made available by NHS Boards, including hospitals, healthcare facilities and premises where NHS Boards use a contractor to manage their car park facilities on their behalf. Those NHS Boards with PFI contracts in place have been asked to enter into discussions with their PFI provider to explore what opportunities exist for limiting or reducing charges for parking. Further work will also be commissioned in conjunction with other statutory and voluntary sector stakeholders in order to:

- Improve public transport links to healthcare facilities
- Raise awareness of the schemes that are available to reimburse travel costs
- Make greater use of new technologies and ways of working to cut back on unnecessary travel.

Self Management

“Life is a bus journey ... you are the driver ... the professional gets on and off.”

Better Cancer Care NoSCAN Roadshow Participant

“Self management needs to be balanced against the appropriate and equitable provision of services for those who cannot self-manage or who do not have carers able to help them on a daily basis.”

Better Cancer Care Consultation Respondent

Gaun Yersel, a Self Management strategy for Scotland, developed by the Long Term Conditions Alliance Scotland, was published in September 2008. This defines self management as "... the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implication of living the rest of their life with one or more conditions." It identifies the different stages at which people need support as:

- Diagnosis – supporting people in coming to the terms with their diagnosis and in making better decisions about their treatment options
- Living for today – supporting people to navigate through difficult treatment journeys and tackling the risks of social exclusion
- Progression – supporting people to respond to fluctuations in the conditions, address changing needs and tackle the psychological issues that so often accompany physical symptoms
- Transition – supporting people as they move between services and helping them to retain control at times of great stress
- End of life – supporting people to meet the range of medical and non medical challenges towards the end of their lives.

“Self-care will require a change of culture; partnership with patients, carers, families and NHS staff; training for staff and patients … be an ‘active participant’, not a ‘passive pyjama’ patient.”

Better Cancer Care Consultation Respondent

The Scottish Government is committed to implementing the actions in this strategy which will benefit all patients with a long-term condition, including cancer patients by:

- Improving quality and access to information available to patients about conditions, clinical services and the wider range of support that is available in local communities
- Introducing personal health plans for people with long-term conditions
- Supporting staff to further develop their communication skills and enable them to deliver care in a more empathetic and holistic way.

“I would have liked a clear roadmap to my patient journey to save worry and confusion, focused on prognosis.”

Better Cancer Care Consultation Respondent

As a contribution to this process, a patient-focused model has been developed in partnership between patients, carers and healthcare professionals. This can be adapted at local level to reflect local needs and the services that are available in a particular community. The model, which is available on the Scottish Government's website www.scotland.gov.uk/bettercancercare identifies the kind of support that patients might require at each stage of their journey, including:

- Useful points of contact
- Prompts about the questions that might be asked or the information that might be provided
- Information and support resources that are available to the patient and/or their carer
- Lifestyle choices and options that might support the patient in considering what they can be doing for themselves.

[There is a] need to recognise that [self-care models] will not suit all patients, but [will] allow those who wish to do so to have the information and support to take on more responsibility for their care.”

Better Cancer Care Consultation Respondent

It is widely acknowledged that Cancer Clinical Nurse Specialists (CNS) play a central role within multidisciplinary management of patients with cancer and other long-term conditions. They are often the one constant factor in the patient's journey and are fundamental to supporting people throughout.

“The ‘Cancer Journey’ can be very lonely and frightening for both the patient and their family. Continuity of care ... and supportive relationships are of equal importance with medical and surgical care.”

Better Cancer Care Consultation Respondent

As the role of CNS has evolved over many years they are in a key position, along with their Allied Health Professional and Cancer Consultant Nurse colleagues to lead developments to support patients to self-manage the effects of both their cancer and side effects such as fatigue, nausea and problems with eating that often accompany their treatment regime. The physical and psychosocial problems experienced by patients need to be addressed by rehabilitation, to effect timely discharge and enable independence in ways that contribute to quality of life and enable the patient to self manage their own health. To support this, a Self Management and Rehabilitation Managed Knowledge Network was launched in 2008. This electronic network enables service users and healthcare practitioners to access knowledge and evidence-based information in relation to Self Management and rehabilitation, which is available at www.enablinghealth.scot.nhs.com

Information and Communication

“The patient journey/pathway is ‘like a washing machine – you are in a spin and information comes at you from all directions’.”

Patient Participant in Supported Self Care in Cancer Consultation Event

“The service in the beginning was superb, but then there was a feeling of abandonment. Unless you know where to go and look, you don't know where to get help. There is good help out there, but you need to know where to go for it.”

Better Cancer Care Conference Workshop Participant

Whilst it is important to remember that all patients are different and not everybody will want to take on greater responsibility for managing their own condition, the discussion that informed *Better Cancer Care* highlighted a general feeling that anxiety can be exacerbated by uncertainty. This uncertainty can be offset, at least in part, by providing the information that patients and their carers want about what is happening to them, where to go, who to see, what to expect and what treatment choices are available.

Example of Good Practice in Scotland

Communication skills are being taught to medical students as part of the medical curriculum. One good example of this is the doctor/patient communication skills class taught to fourth-year medical students at Edinburgh University in training at the Western General Hospital. This class involves participation by patient volunteers who share their experiences of doctor/patient communication. This gives young doctors the chance to come face to face with patients in a non-clinical setting and to better understand the dynamic between them and their patients.

There are a number of routes through which patients and carers might choose to get such information and the challenge facing NHSScotland and its partners is to ensure that each of these routes are as accessible as possible and that the information they offer is of a consistently high quality. The development of a National Health Information and Support Service which is due to be launched in 2009, provides a unique opportunity to ensure that patients and their carers can receive consistent, high quality information regardless of whether they chose to access this in print, face to face, over the telephone or electronically. Written communications (in print or web-based) may not however be appropriate for all patients and their families; research shows that over half the population in Scotland have low reading skills, including people who cannot read at all and those who can only read very simple text and this must be considered when information is developed.

Equally Well stated that NHS Health Scotland should deliver an accessible communication, translation and interpreting strategy and action plan, with clear outcome measures and expectations on good practice. All NHS Boards have made some progress in this respect and there is a great deal of translated information available from national condition-focused charities and other resources and stakeholders. However, there remains a requirement for a centrally co-ordinated approach and therefore the Scottish Government will work with stakeholders to develop a web resource which will gather, hold, manage, make available and develop a body of health information in a variety of languages and formats, including British Sign Language. This resource will be developed along the lines of the 'polishinformationplus' proof of concept project www.polishinformationplus.co.uk developed by a partnership led by the Scottish Consumer Council and tried and tested during 2007.

"We know from our work with disabled people, and those who do not speak English, or have it as a second language, that communication remains a major issue.... Improving staff awareness of the needs of everyone they may meet is crucial to putting patients at the centre."

"Often the wrong sort of communication support is booked if hospital staff are unaware of the person's needs. This adds to an already stressful situation ... [Therefore they would] not have the opportunity to make informed choices about treatment due to a lack of accessible information."

Better Cancer Care Consultation Respondents

Example of Good Practice in Scotland

Now We're Talking: Interpreting guidelines for staff of NHSScotland has been distributed to GP practices. The guidelines include different language needs of patients and the importance of providing an interpreter to patients, as well as outlining different types of interpretation and how NHS professionals can work effectively with interpreters.

Inter-professional Communication

Communication with patients and their carers needs to be underpinned by communication between different professionals involved in the care of cancer patients. The consultation that informed Better Cancer Care highlighted a number of occasions where patients felt that their experience of care could have been improved by better communication between the people who supported them. Such messages pose a cultural challenge to NHSScotland. Staff groups, with the support of NHS QIS, are working to implement existing inter-professional communication standards and extend the coverage of such standards to all tumour types.

Psychological Support

Cancer and cancer treatments are known to have a significant impact on psychological wellbeing, as does the physical pain associated with these. Pain may also affect the person's psychological wellbeing and this must be addressed in order to improve their quality of life. In November 2008, Scottish Intercollegiate Guidelines Network (SIGN) will publish SIGN 106 - *Control of Pain in Adults with Cancer a National Clinical Guideline*.

Psychological factors are integral to meeting needs for the exchange of information, responding to emotions, managing uncertainty, making decisions and enabling people with cancer to manage the impact on their lives.

Good psychological support services can support both patients and their carers at every stage of their cancer journey. People with cancer expect that psychological distress, concerns and symptoms will be acknowledged and identified and that they will be supported to access care, support and intervention that is appropriate to their level of need. All staff should have a basic level of knowledge and skill in psychological care for people. A survey exploring suicidal and distressing thoughts further highlights the need for psychological support. This study involved 2,900 UK cancer patients and found that 8% had recently felt they wanted to die or badly hurt themselves, which is three times more than the general population. As such, staff who are involved in providing more specialist psychological care need to have adequate support, training and supervision to enable them to achieve this.

Care systems, protocols or pathways should be developed to ensure that psychological needs are actively considered as a part of planning care. This is particularly important for patients who need reconstructive care due to changes in their physical appearance caused by treatment. Some patients are at greater risk of developing severe psychological reactions and problems. These patients need to be identified and cancer services should have access to a range of psychological support and interventions strategies to reflect the range and complexity of psychological needs. NHS Boards and regional cancer networks will be encouraged to ensure that all patients with cancer have an assessment of their psychological care needs and that tailored responses are developed as part of personal care plans. This work should be developed in partnership with the voluntary sector and with specialist psychological care practitioners such as clinical health psychologists and liaison psychiatrists.

Carers

The support of family and friends as unpaid carers is crucial to the wellbeing of many people living with cancer and the Scottish Government regards carers as partners in the delivery of care. However, it is also recognised that many carers need support to balance caring with other responsibilities, without putting their own health at risk. That is why the Scottish Government is making an investment that will increase to £5 million per year in 2010/11 to support local NHS Carer Information Strategies. This will help identify carers of all ages at an early stage and enable them to access support, information and training, whilst at the same time looking after their own health. Many NHS Boards are complementing their strategies by operating a Scottish Enhanced Services incentive for GPs to compile a register of carers, to identify their needs and refer them to sources of support.

Carers, regardless of their age, whose caring role is substantial and regular, have the right to get their support needs assessed, independent of the person they are caring for. The Scottish Government recognises the importance of breaks from caring (or respite) and the high priority carers tend to place on the issue. A consultation by the Scottish Government on its revised short breaks guidance to improve local planning of personalised, preventative breaks which meet the needs of both the carer and cared for person has taken place and the revised guidance will be published in 2008.

The Scottish Government is providing local authorities with more funding to develop their services, including services for carers, based on local needs and priorities. There is an agreement with the Convention of Scottish Local Authorities that local authorities will provide an extra 10,000 respite weeks per year by 2010/11.

It is vital that services recognise that children with a parent or sibling living with cancer may also have a caring role. Under their *Carer Information Strategies*, NHS Boards must ensure that they have measures in place to ensure young carers are identified early and are signposted to sources of local support. In addition, the new guidance and resources will also help to extend personalised short breaks for young carers, including those affected by cancer.

The Voluntary Sector

Better Health, Better Care made clear the Scottish Government's determination to work in new and different ways with the voluntary sector. It announced a strategic review of the current and potential future role of that sector in the design and delivery of high quality health and care services. This is expected to be completed in partnership with representatives of the sector by Summer 2009. The lead role played by the Long Term Conditions Alliance Scotland in the development of *Gaun Yersel* demonstrates what can be achieved by working together and the creation of a new self management fund proposed in that document, will provide direct financial support for voluntary organisations and community groups in supporting self management for cancer and a range of other conditions.

The Scottish Cancer Coalition, established in 2003, is a partnership of 19 organisations that improve cancer services and outcomes for patients in Scotland, and to promote research and prevention efforts. The organisation exists to ensure the needs of people living with and beyond cancer in Scotland are met. Member charities have a range of expertise and experiences, but have a shared vision for collective action to make a difference for cancer patients in Scotland. The Scottish Cancer Coalition celebrates the strength and diversity of the voluntary sector and between them provides support, information and advice to thousands of people affected by cancer each year. The Scottish Government will continue to work with and support the voluntary sector to enhance existing services for patients.

The *Enterprising Third Sector Action Plan 2008–2011* sets out a range of actions to create the environment in which the voluntary sector can maximise its contribution to a successful Scotland. This includes support for volunteering, the development of strategic partnerships with national organisations to enable them to contribute effectively to Scottish Government policy and the commitment to opening markets, investing in skills, learning and leadership, supporting business growth and promoting social entrepreneurship.

Palliative Care

The World Health Organization (WHO) defined palliative care as, “*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*”

Palliative care is therefore an integral part of the care delivered by any health or social care professional to those living with and dying from any progressive and incurable disease. It is not just about care in the last months, days and hours of a person's life, but is also about enabling someone to live with a life-threatening condition, maintaining and (as far as possible) improving quality of life for patients and their families. As well as controlling pain and other distressing symptoms, it is about helping patients and families cope with the emotional upset and practical problems of the situation, helping people to deal with spiritual questions which may arise from their illness, and supporting families and friends in their grief and bereavement.

“Many patients think that if treatment is being given, there is ‘hope’: i.e. of a cure, when this is in fact not possible. Clinicians have to learn how to be more honest, while also being compassionate. This is extremely difficult, but in the end both patients and relatives will appreciate the truth, and thus be able to make appropriate end-of-life decisions.”

Better Cancer Care Consultation Respondent

“It’s not all about making someone immortal – it’s about making someone comfortable.”

Better Cancer Care Fair for All Religion Belief Roadshow Participant

Living and Dying Well, A National Action Plan for Palliative and End of Life Care in Scotland was published in October 2008. This builds upon work by the Scottish Partnership for Palliative Care and the recommendations of a wide-ranging review of palliative care services by Audit Scotland, published in August 2008. NHS Boards have appointed executive level leads for palliative and end of life services to support the implementation of this plan in partnership with Palliative Care Networks and Community Health Partnerships. In order to ensure that *Living and Dying Well* and Better Cancer Care are delivered in an integrated way a member of the Scottish Government Health Directorates Advisory Group on Palliative and End of Life Care will take a role in new national governance arrangements being established to support the cancer plan.

We will:

- Under the direction of the Scottish Cancer Taskforce, establish a working group on survivorship to maintain the national focus on this issue and identify requirements for further research
- Work towards referral to benefits and financial advice, incorporating a financial situation assessment, becoming a systematic part of the patient journey
- Work with MacMillan Cancer Support to develop the work of benefits advisors throughout Scotland, including new funding to extend services in new ways to remote and rural communities
- Work with MacMillan Cancer Support to develop a pilot employability project to support people with cancer to enter and sustain employment in environments which reflect their needs
- Implement the actions described in the new Self Management strategy for Scotland in conjunction with the Long Term Conditions Alliance Scotland and the Scottish Cancer Coalition
- Promote the use by clinicians, patients and carers of the new self-care model for cancer in Scotland
- Ensure that effective patient information on cancer is prioritised within the development of the National Health Information and Support Service
- Develop a central web resource for information in different languages and formats including British Sign Language
- Seek ways to improve and speed up communication to patients and between professional disciplines and services
- Work with RCAGs and NHS QIS to support the implementation of the existing standards on inter-professional communication and extend the coverage of such standards to all tumour types
- Implement guidance on short breaks for carers.



SECTION EIGHT:

IMPROVING QUALITY OF CANCER CARE FOR PATIENTS

8. IMPROVING QUALITY OF CANCER CARE FOR PATIENTS

Significant progress has been made in improving cancer services since the 2001 cancer plan. Managed Clinical Networks (MCNs) have been established, with a remit to improve the quality of care of patients, as outlined in HDL (2001)71 *Cancer in Scotland: Action for Change: Regional Cancer Advisory Groups (RCAGs)*. NHS QIS has a role in ensuring the consistency and quality of treatment provided by MCNs through the accreditation process, and this responsibility was further enhanced in HDL (2007) 21 *Strengthening the Role of Managed Clinical Networks*. Networks play an important role in self scrutiny to improve services locally, regionally and nationally. MCNs should take the lead in ensuring the implementation and ongoing monitoring of advice and guidance from NHS QIS (including national standards and SIGN guidelines). This will provide local services with accurate local data which can be used in a timely manner to improve the effectiveness and efficiency of their services and individual performance.

MCNs are required to assess how services within their geographical areas perform against these standards. In addition, RCAGs have coordinated this activity and published reports detailing the progress of their cancer services. The areas of work included:

- Improving patient and public involvement in shaping the work of the networks
- Audits of multidisciplinary working and multidisciplinary team meetings
- Education events
- Clinical audit and monitoring
- Service improvement and redesign.

The consultation responses indicated a strong degree of consensus that there is a need to do more to improve the engagement between those who provide services and those who use them. Many respondents also made the point that there should be an extension of quality standards to non-clinical aspects which may include physical, psychological, social and spiritual care. An editorial in the Scottish Medical Journal highlighted the importance of ensuring that clinical audit is supported as it underpins the activity of each tumour network and is the key to clinical improvement. Therefore a quality programme must be developed, based on the NHS QIS core and tumour specific cancer standards, to drive improvements both in clinical and non-clinical aspects of care. Through the implementation of these cancer standards across all tumour sites, continual quality improvement will be achieved.

As part of the NHS QIS accreditation process, Regional Cancer Networks have developed quality assurance frameworks that cover a wide range of issues, such as:

- Reporting and accountability
- Involvement of the public
- Clinical audit and governance arrangements
- Educational programmes.

These regional frameworks provide the basis for the development of a comprehensive national quality programme, so that services are provided to agreed standards, whilst allowing flexibility for Networks to address specific local and regional issues.

A Broad Approach to Quality

Better Health, Better Care sets out the basis for NHSScotland's approach to quality improvement. This is based on the Institute of Medicine's definition for quality and has six specific goals:

- Patient-centred – considers the patient's preferences and requests in every health care decision regarding diagnosis, treatment and care
- Safe – helps cure the patient instead of causing more injury or discomfort
- Effective – provides the right services to the right people, only when they really need them
- Efficient – targets the application of resources (staff, supplies, equipment) to maximise resource use and avoid passing on costs to the patient
- Equitable – ensures that every patient receives the same standard of care regardless of gender, ethnicity, geographical location and socioeconomic status
- Timely – provides treatment quickly, reducing waits and (sometimes harmful) delays.

The future work programme for quality improvement in cancer services needs to reflect all six dimensions of this model, which are both interlinked and essential, thereby providing a clear focus on quality at national, regional and local level.

Putting Patients at the Centre

NHSScotland's commitment to becoming a more mutual organisation puts the participation of patients and their carers at the heart of its continual drive to improve the quality of healthcare services. The importance of putting the experiences of patients at the centre of decisions on the planning and delivery of cancer services was reinforced in the Scottish Government-funded research published by the University of Stirling in 2008. This research confirmed the importance of the agenda described in the previous chapter in the way that it challenges NHSScotland to:

- Develop services that treat the person and the disease
- Deliver services in a way that ensures a cooperation between the expertise of professional, patients and the public
- Strengthen joint working between tertiary, secondary and primary care and expand partnerships to include social care, employment and welfare agencies.

“To improve the patient’s experience we must learn from their experiences. Satisfaction surveys could be used to gauge how well the service is doing, and highlight the areas for improvement.”

Better Cancer Care Consultation Respondent

“Reassurance is required about the patient’s wishes being fulfilled ... professionals should be aware of the importance of [cultural] issues. Doctors should be educated [in the various cultural expectations/issues] so they can have more open conversations with patients.”

Better Cancer Care Fair for All Disability Roadshow Participant

Better Together, the Scottish Patient Experience Programme launched in February 2008, aims to gather information on the experiences of patients and uses the insights and understanding these provide to make and prioritise improvements in the way in which care is designed and delivered. As part of Better Together, NHS Boards will:

- Actively seek the views of patients and what they wish from cancer services
- Conduct regular surveys to qualitatively and quantitatively assess the ways in which they are responding to user views
- Provide evidence that the information already collected (for example, from Patient Focus Public Involvement work and complaints procedures) is being used to direct learning opportunities and embed improvements into local cancer services provision
- Ensure that they involve those who may not normally engage in consultation exercises, including, for example, older or younger people, black and ethnic minority groups and lesbian, gay, bisexual and transsexual (LGBT) groups
- Demonstrate partnerships between patients and healthcare professionals in policy making, quality assurance and the evaluation of services.

The Better Together programme will involve the development of pilot improvement materials around cancer, which will allow patients to share their experience online. This will be fully monitored and regularly fed back to NHS Boards. Further information on the objectives, benefits and specific activities over the next three years is available on www.infoscotland.com/bettertogetherscotland/CCC_FirstPage.jsp. The key areas where experiences of people affected by cancer will be expected to have an impact are:

- At presentation of suspicious signs and symptoms and handling of concerns around the time of referral, further investigation and diagnosis
- During decision making about treatment options
- At the stage of active management of the disease
- At the transition point when an intense treatment phase is completed
- Getting ‘back to normal’, including rehabilitation and adjusting to life after treatment
- During surveillance and monitoring for recurrence

- In the detection and management of treatment related side-effects including 'late effects'
- When symptom palliation is required or when end of life issues become paramount.

Example of Good Practice in Scotland

Patient Improvement Work

South East of Scotland Cancer Area Network (SCAN) has been capturing patient stories to inform their service improvement work around streamlining the patient pathway and reducing waiting times. Using a modernisation technique called 'Discovery Interviews', interviews have been conducted with lung cancer patients and their carers across Lothian and Dumfries & Galloway. Patient feedback is 'anonymised' and then shared with the clinical teams, so that key priorities can be included in service improvement action plans.

"Priority should be given to involving patients in the development of all information, which should be provided in a variety of formats and languages in order to be accessible to all sections of society."

"There is a great concern that [this patient] involvement is currently limited to the 'usual suspects'. We need to look at new ways of involving and listening to younger people affected by cancer, using a range of communication methods such as, phone, SMS and the Internet, rather than relying on local meetings alone."

Better Cancer Care Consultation Respondents

If patients have a bad experience of care, it is important that they can access good quality advice and support. The Independent Advice Support and Advice Service was launched within Citizens Advice Scotland in September 2007 to:

- Help people understand the NHS and what their rights/responsibilities are
- Assist people (particularly the more disadvantaged) to engage with the NHS
- Ensure help and support is available to patients, carers and members of the public to raise concerns with the NHS care provider and resolve issues informally
- Guide patients through the formal NHS complaints procedure and provide information and support they need to access and make better use of NHS services
- Encourage better communication and learning from patient experience and feedback in developing patient-focused services.

Patient Safety

Patient safety is a major, strategic development priority for NHSScotland. An explicit and tested approach to improving patient safety has the potential to greatly improve the quality of care and the patient experience, providing patients with the confidence that when they access any part of the healthcare system they will receive the best treatment

reliably and without fear of harm. By adopting a nationally-led, strategic approach, significant levels of sustainable improvement are envisaged. This will be achieved through a major change programme based on integrated arrangements at national, regional and local levels.

The complexity of cancer care provision (including the provision of palliative and end of life care services) demonstrates the importance of ensuring safe and effective practice is the norm, with an increasing focus on the reliability of the processes underpinning that care. The Scottish Cancer Taskforce will work with the Scottish Patient Safety Alliance to identify key issues for cancer services at a local, regional and national level. It will report progress on these issues in its annual report.

Clinical Effectiveness

Each level (local, regional and national) in NHSScotland should understand their role and responsibilities and should also strive to make the best use of its resources, minimising duplication where possible. National Cancer Audits and comparative reporting have already proved successful at identifying real improvements in patient care. There are a number of lessons which can inform how best to achieve quality improvement from audit:

Learning Points from ISD National Audits of Other Diseases

- The audit must have clear and explicit aims and objectives stating what aspect(s) of patient care the audit aims to improve and how these will be assessed
- It is good practice to have a clinical governance framework in place for the audit to demonstrate it has a process for ‘closing the audit loop’
- It is good practice to identify, measure and report on any quality standards
- The audit must be applicable nationally (if not national to start with) – there should be a national database of the core data required by the audit
- Any comparative results should be presented openly
- Minimise additional work by clinical and other staff involved in data collection
- Outline how feedback will be provided to clinical teams and managers, how improvements in care will be supported (for example, the frequency of reporting required to support quality improvement)
- Identify how the audit will be mainstreamed into clinical care, if applicable

There is a need to benchmark audit outcomes across regions and providers in order to improve care to the very highest standards. ‘National Indicators’ based on standards will be common to the three regional cancer networks. In addition to comparing data within each network, data should be compared between the three cancer networks, in order to produce a national picture. Moreover, where a UK audit exists, for example, LUCADA (Lung Cancer Audit Data Analysis), the networks will endeavour to collect data which will enable accurate comparisons to be made. There is also a need to ensure that many different types of tumours are included in the national, regional and local audit programme.

The 'cancer journey' for many people starts when they notice symptoms, so audit should therefore examine the total patient pathway from when the patient presents with symptoms to post-treatment. Lessons must be learned from the primary care audits to encourage people to see their GPs earlier, to enable faster referral into diagnostic and treatment services. In addition, primary care and screening audits need to be part of the quality process as they impact at different stages in the whole cancer pathway. The data gathered from these audits should be used by primary care to improve quality, processes and patient outcomes.

The Scottish Cancer Taskforce will be asked to develop a national quality work programme which will include a review of audit resources and tasks across Scotland, actions to streamline the process to reduce duplication of information and defining a rolling programme of audit, together with a governance framework, to ensure the audit outcomes are acted upon.

Efficiency

Reducing waste and duplication in cancer services is a priority and an important dimension of quality improvement. With the support of the Scottish Government's Improvement and Support Team, there are a number of areas where the efficiency of the process of care will be examined and services redesigned where necessary. A significant amount of work has already been done by local teams in mapping out patient pathways in support of the 62-day waiting times target. This includes optimising e-referral, streamlining or eliminating referral triage, on-line referral triage, establishing models of straight to test, ensuring clear outcomes from multi-disciplinary meetings and improving scheduling and sequencing of key diagnostic tests and appointments. Extending the benefits of the 62-day pathway to screened positive patients will extend this redesign of services to screening services ensuring that screening teams are supported to identify and tackle their service delays and bottlenecks. All NHS Boards will continue to be encouraged and supported to better understand demand and capacity for cancer services and to ensure that planning for cancer services takes place within the context of other major system changes such as the 18 Weeks Referral to Treatment Standard which will take hold from 2011.

Work will also be done in the planning of radiotherapy workload. All of these initiatives will be supported by NES to ensure there is a robust training plan, relevant to the needs of staff working within cancer services. These pieces of work will be highlighted in the Scottish Cancer Taskforce annual report, where progress will be outlined.

Equitable Care

“Patients want to know that the treatment they receive locally is as good as any in the country.”

Better Cancer Care Consultation Respondent

Multi-disciplinary teams that work within regional MCNs were introduced in the early 2000s to minimise geographic inequalities in the quality of care and to ensure the highest standards of care were provided throughout Scotland.

NHS QIS, together with the cancer networks, have already progressed and developed a range of standards for some cancers. Publications in 2008 have included standards for lung, colorectal, breast and ovarian cancer. The Scottish Cancer Taskforce will consider other areas where there is evidence of variation in care/outcomes and work with NHS QIS to prioritise the development of standards.

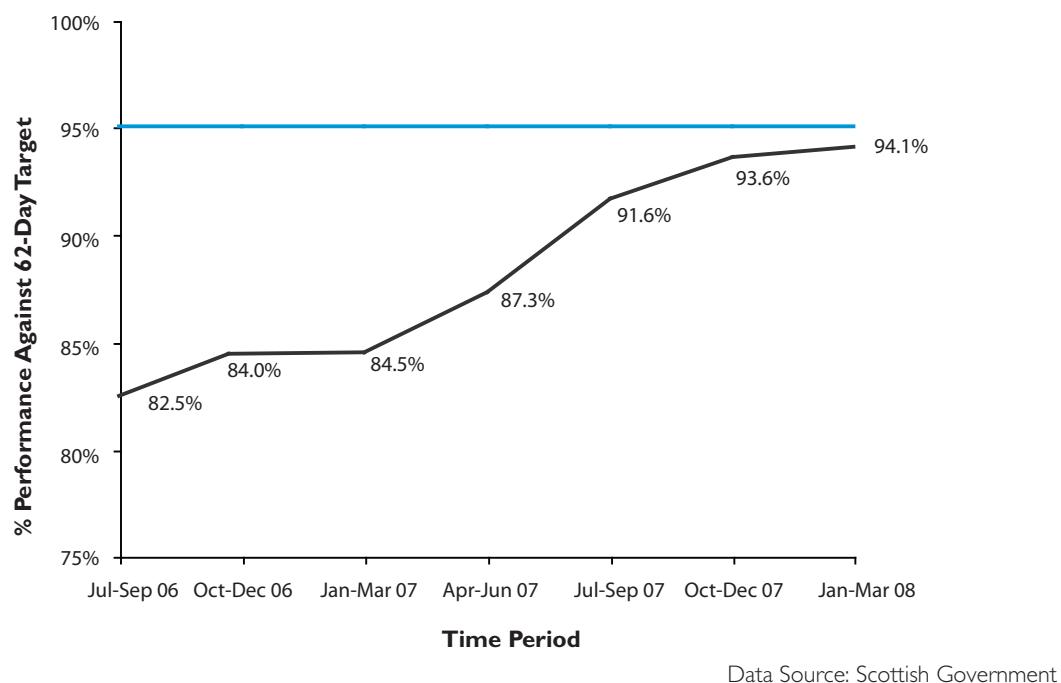
There is a growing expectation from patients that all care can be delivered closer to home and the Scottish Government believes that decisions about the configuration of services should be made on the basis of a presumption against centralisation. Providing seamless care involving shifting the balance of care closer to the patient's home will require Community Health Partnerships (and Community Health Care Partnerships) to have a greater role in the planning and delivery of service for people with cancer in their areas. There are however, circumstances in which it makes sense to concentrate certain services for the benefit of patients, as patient safety must be paramount at all times. Whilst some treatments can be delivered in local hospitals, other treatments require such highly-specialised support and facilities, that they can only be safely provided in the five main cancer centres.

Timeliness (Access)

There is a continuing call from patients and their families to reduce waiting times – time from referral to being seen by a consultant or other healthcare professional, time for investigations and time from diagnosis to treatment. It is important to acknowledge that the links between specific waiting times targets and better outcomes in terms of long-term survival are generally unclear. However, there is no doubt that waiting times are closely linked with increased anxiety and concern for patients and their families and that waiting is an important component of quality.

Scotland currently has four cancer waiting times targets set out in *Our National Health, A Plan for Action, A Plan for Change* (2000). The 31-day targets for both children's cancers and acute leukaemia have been achieved and sustained (at the time of publication). The 31-day target for breast cancer has not yet been achieved but NHS Boards are focused on improving this part of the pathway. The 62-day target for urgent referral to treatment for all cancers has shown significant improvement in 2007/08 (Figure 16); the last quarterly validated figure (January to March 2008) shows 94.1% performance against the 95% target.

Figure 16: NHSScotland: all cancers – performance against 62-day urgent referral to treatment target



Improved performance over this period has been due to a number of different strategies implemented across NHSScotland. Weekly performance reporting has provided NHS Boards with the information they need to manage performance and identify problems and bottlenecks in patient pathways. Timed pathways have been put in place for each individual tumour site to ensure that patients are proactively managed through the 62-day pathway. Local escalation procedures have been implemented to ensure that delays can be avoided as far as possible. In addition, inter-hospital transfer protocols (where patients are referred between hospitals and NHS Boards for assessment, investigations and treatment) have been agreed. Nationally, the Cancer Performance Support Team was established in November 2006 to provide support, along with a performance management function, to NHS Boards and has worked closely with a number of NHS Boards to identify and resolve problem areas locally. The renewed focus and direction has assisted in the significant improvement against the target; the key for the future is for NHSScotland to sustain this.

“Waiting times [need to be] more inclusive and meaningful for patients and healthcare professionals.”

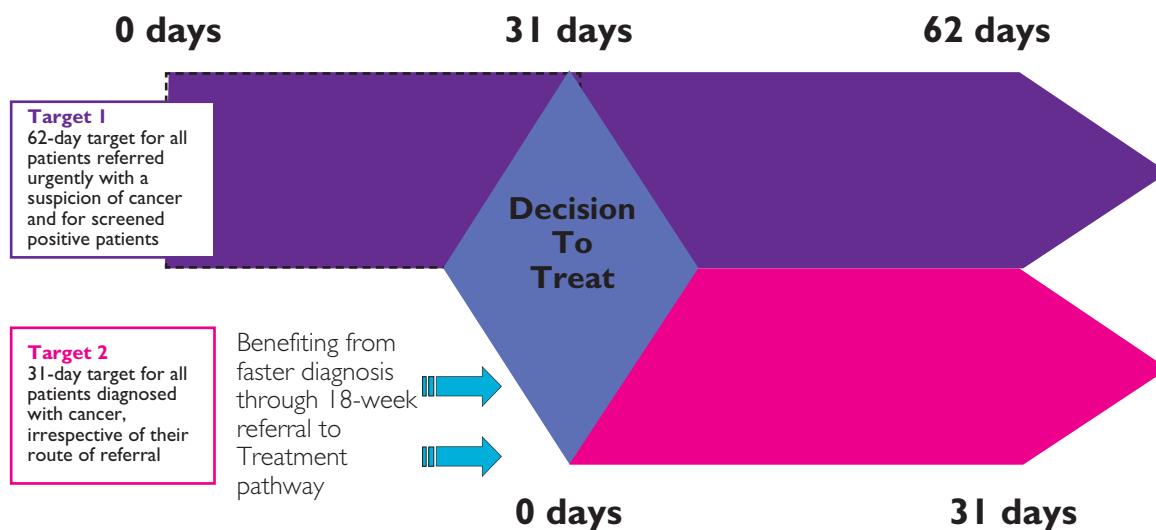
Nicola Sturgeon, Cabinet Secretary for Health & Wellbeing,
at the launch of *Better Cancer Care, A Discussion*

Taking account of the responses from patients and the voluntary sector to the *Better Cancer Care, A Discussion* document and consultation with a range of individuals within the services, the scope of the current waiting time targets will be extended.

First, the urgent flow of patients covered by the 62-day target will be extended to include screened positive patients, which will ensure equity for patients who display symptoms suspicious of cancer and will encourage the redesign of screening services along the whole patient pathway.

Second, building on the improvements achieved in patient pathway management for the urgent flow of patients, urgent and routine flows of patients will come together from the point of decision to treat to benefit from a new, comprehensive 31-day target. This means that access from decision to treat to first definitive treatment will be the same for all cancer patients, whatever their flow into the system. The definition of the 'decision to treat' date will require further work to agree the starting point for this target which is most meaningful to patients. In many cases, this is likely to be the date on which a multidisciplinary team consensus on treatment plan options is discussed and agreed with the patient. This new target which is already a milestone for the urgent flow of patients on their 62-day pathway (Figure 17), will cover all patients referred either as urgent, routine or from a cancer screening programme. This will ensure greater equity between all patients diagnosed with cancer, irrespective of their flow into the system.

Figure 17: New waiting times targets



The proposed changes to the targets will be taken forward alongside the work on the new 18 weeks referral to treatment standard (which will further accelerate diagnosis for all routine patients in Scotland whether or not they are found to have cancer) to ensure that resources are used appropriately and integrated across all access targets.

The overall aim is to support continual improvement in cancer control and quality of cancer care; timeliness and access are integral to a quality service, focusing on what is meaningful for patients.

We will:

- Develop a work programme which will define how we will take forward the six quality indicators for cancer services
- Work with the Scottish Patient Safety Alliance to identify key patient safety issues for cancer services at a local, regional and national level
- Work with the *Better Together* team to progress the objectives, benefits and specific activities over the next three years, to improve the experiences of people affected by cancer
- Review audit resource across Scotland and reduce unnecessary duplication
- Convene a short-life working group about how we will develop a work programme for quality improvement
- Ensure by 2010, all tumour networks take part in national audit and agree a governance framework with RCAGs and their constituent NHS Boards about how the results of these audits are acted upon locally
- Extend the 62-day urgent referral to treatment target to include screened positive patients and all patients referred urgently with a suspicion of cancer (to be delivered by 2011)
- Introduce a new 31-day target for all patients diagnosed with cancer (whatever their route of referral) from decision to treat to treatment (to be delivered by 2011).



SECTION NINE: DELIVERY

9. DELIVERY

Better Cancer Care

Better Cancer Care maps out the key priorities and actions for tackling cancer in Scotland. By necessity it is a broad plan which requires the involvement of NHSScotland and the people who work within it, other parts of the Scottish public sector, the voluntary sector and of course, patients, carers and others who are affected directly by cancer. If this plan is to achieve the outcomes and deliver the benefits it seeks, it needs to be underpinned by a strong and determined focus on delivery, supported by structures and processes that direct the attention of all stakeholders on delivering outcomes and minimising the risks to delivery across Scotland.

Scottish Cancer Taskforce

The implementation of this plan will be overseen by a new Scottish Cancer Taskforce, chaired by the Deputy Chief Medical Officer. This will replace the Scottish Cancer Group and provide a focal point for the actions in this plan, provide support and advice to NHS Boards and the RCAGs and ensure that patients, NHS staff, the Royal Colleges and the voluntary sector continue to have a strong voice in advising the Scottish Government and NHS Boards on cancer issues.

“There should be better engagement between professionals and users. Patient and carer experience should be central to planning. There should be workshops with the Scottish Government to agree quality indicators and cancer targets.”

Better Cancer Care Consultation Respondent

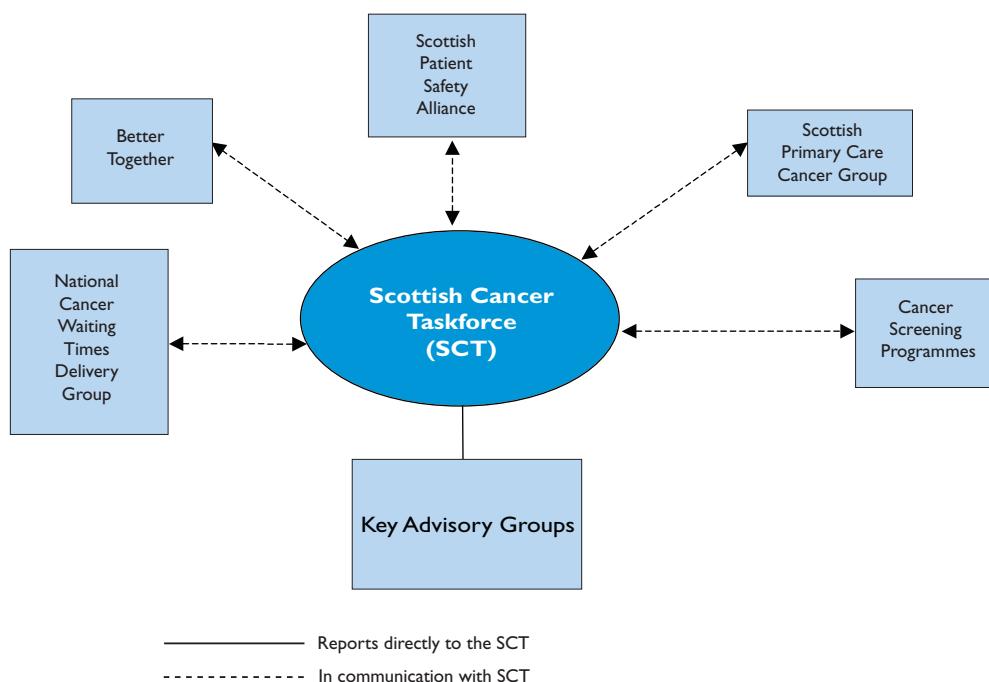
The first task of the new group will be to review the rest of the cancer 'delivery landscape' (Figure 18) and to identify ways in which the current network of advisory, planning and delivery groups can be streamlined in order to ensure that they are best able to support the effective and efficient implementation of this plan. In particular, this review will need to demonstrate how the delivery and subsequent development of the actions in this plan will continue to be informed by patients and the public more generally and be fully integrated within the planning processes and priorities of NHSScotland at board, regional and national level.

Subject to the conclusions of this initial review, it is envisaged that the key, ongoing tasks of the new Scottish Cancer Taskforce will be to:

- Agree an annual work programme with key advisory groups to ensure that actions are delivered and that the Scottish Government and NHS Boards have access to the latest advice and expertise
- The future work programme for quality improvement in cancer services will reflect the six dimensions of quality
- Work with Patient Safety Alliance, Better Together and the National Cancer Waiting Times Delivery Group to improve the patient experience, ensure the highest standards of patient safety and advise on waiting times issues

- Ensure that the plan is implemented in a way that supports NHSScotland's commitment to equality and diversity
- Provide guidance on taking forward the national audits set out in this plan
- Identify and advise the Scottish Government on the implications and opportunities arising from NHS Board and regional workforce and service delivery plans, including the identification of priority education and training needs
- Provide advice to eHealth and Telehealth teams within Scottish Government and NHS Boards to support the design and implementation of solutions which enhance services for patients and clinicians.

Figure 18: Links to Scottish Cancer Taskforce



Clinical Leadership

There was much debate during the *Better Cancer Care* consultation process about the need for clinical leadership to deliver this plan. The appointment of the Deputy Chief Medical Officer as Chair of the Scottish Cancer Taskforce provides the opportunity of providing such leadership at the very heart of Scottish Government. The Taskforce will also include the three regional clinical leads for cancer, together with the Chair of the Scottish Primary Care Cancer Group who, with the Deputy Chief Medical Officer, will further enhance clinical leadership by developing a national component to their respective roles and in particular:

- Advise the Scottish Government about key clinical issues and ensuring that work in such areas is coordinated appropriately at a national level
- Work with Directors of Nursing and Allied Health Professional leads to ensure that all NHS professional groups' views are appropriately represented at a national level

- Facilitate the ongoing involvement of regional and local lead clinicians in developing and delivering the broad programme of quality improvement envisaged by this plan
- Represent the views of local and regional clinicians at a national level to deliver the quality programme outlined in this plan.

Regional Cancer Networks and Managed Clinical Networks (MCNs)

MCNs facilitate clinical collaboration across Scotland and are a key feature of the more mutual NHS described in *Better Health, Better Care*. They have strengthened significantly over the past seven years and enabled professionals to share effective clinical practice and develop consistent treatment protocols. NHS Boards collaborate in planning cancer services under the auspices of three regional cancer networks (NoSCAN in the north of Scotland, SCAN in the south east and WoSCAN in the west). These networks offer the opportunity to take shared planning decisions and enable individual NHS Boards to maximise the effectiveness of their investment in cancer services. The regional cancer networks will continue to report their progress on their respective websites and through the publication of annual reports.

The *National Delivery Plan for Specialist Children's Services in Scotland – a Draft for Consultation* stated children's cancer services in Scotland should be planned on a national basis through the National Managed Clinical Network, and delivered according to the levels of care described in *Option Appraisal for Children's Cancer Services in Scotland, 2008*. This National Managed Clinical Network should operate on a permissive basis that facilitates the delivery of local 'shared care', the development of care pathways and progression of measures targeted at supporting the progressive improvement in patient outcomes. The service pattern for Scotland will be developed in accordance with the guidance set out in the *National Delivery Plan for Children and Young People's Specialist Services in Scotland* which will be published later in 2008.

Workforce Planning

Effective workforce planning is required in order to quantify the numbers, skills and levels of expertise of staff currently within NHSScotland and enable NHS Boards both individually and collectively to prepare for changes in the services they offer and the ongoing need to replace those staff lost through retirement or from leaving the service. *Better Health, Better Care: Planning Tomorrow's Workforce Today* set out a number of key actions that must be undertaken at NHS Board, regional and national levels to ensure that the workforce in NHSScotland has the capacity and capability to meet current and future demand for health services. As a key clinical priority, it is vital that such approaches recognise both the future demand for cancer services and the skills and new roles that will be required to meet such demand.

The Career Framework and its links with the Knowledge and Skills Framework for NHS Staff offer opportunities to ensure close integration with the processes of service planning at NHS Board, regional and national level. Work is underway within NES and Skills for

Health to support this process by providing tools that will assist in the identification of competences needed for the delivery of cancer services, for example, ward-based and outpatient services, chemotherapy and radiotherapy services. These tools will allow planners to model multidisciplinary staff teams and plan for an improved skill mix which will deliver quality care. This will allow the development of competence-based job roles and will provide an approach to quantifying the number and type of new roles needed. It is acknowledged that this must be supported by continued investment in education and training.

To support workforce development, NES has developed a capability framework for cancer care. The framework, which will be published in late 2008, can be used by staff at different levels to identify learning needs, for self assessment and planning personal development, for team development and as a guide to developing education and training.

A coherent and strategic approach needs to be taken to workforce planning, development, education and training. NES, in conjunction with workforce planners and the service will have a critical role to play in taking this forward. Education and training are essential in meeting workforce development needs. NES will continue to work closely with the three RCAGs to identify their workforce education and development needs and support RCAGs in devising educational solutions to meet these needs in collaboration with the Scottish Cancer Taskforce.

“The role of the surgical team members need to evolve; extended roles for nurses would allow surgeons more time. There should be national planning of surgical services and conglomerations of expertise to ensure best results.”

Better Cancer Care Consultation Respondent

A key priority for workforce planning will be to ensure that plans for the surgical workforce include, not only the need for surgical consultants and trainee surgeons, but also those for the wider multidisciplinary team, including nursing and allied health professionals (AHP) staff in wards and theatres, pharmacy, healthcare scientists and facilities staff. Action is also required to promote and ensure the development of new roles such as healthcare support workers and assistant practitioners, along with effective educational programmes that will enable NHS Boards to meet the objective of delivering safe and effective chemotherapy services closer to the patient's home. The *NES Workforce Education and Training Framework for the Safe Use of Cytotoxic Medicines* (2007) promotes the safe use of cytotoxic medicines and supports implementation of national guidelines, particularly HDL (2005) 29 and HDL (2004) 30 *Safe Administration of Intrathecal Cytotoxic Chemotherapy*. It is equally applicable to primary and secondary care settings and staff working with adults and children. It provides the foundation for a consistent approach to education and training across Scotland. The Scottish Government is committed to the utilisation of this framework for the benefits it brings to patient care.

Radiotherapy requires a mix of skills from a range of staff, including clinical oncologists, therapeutic radiographers, medical physicists, healthcare scientists, nurses, radiotherapy assistants, helpers and administrative and clerical staff. A priority for workforce planning is to redesign the radiotherapy workforce through a focus on skills and competence (rather than job titles) in order to address staff shortages and recruitment difficulties in some areas.

Implementation of the Society and College of Radiographers 4-tier career progression framework has progressed over the last few years but has not been consistent across Scotland. This is particularly disappointing, as centres that have implemented it have demonstrated the model can reduce waiting times for patients, aid recruitment and retention of staff and increase capacity. Maximising the potential of the 4-tier model should be progressed by NHS Boards, with continued support from NES and other partners.

eHealth

Clinical care requires a variety of sophisticated data capture, information storage and communication processes. Communication, in particular, is a key challenge, given the wide range of contributors to care and the number of different organisations involved. IT related support for these processes, which has come to be known as 'eHealth', has in the past, involved a mixture of manual and various eHealth support systems across NHS Board areas.

Greater consistency has now been achieved, for example, with an ever increasing proportion of GP referrals now being made electronically via the 'SCI Gateway' IT system and each NHS Board's 'SCI Store' is increasingly being used for accessing test results. The national Picture Archive Communication System (PACS) is also being rolled out, which supports the transfer of digital x-rays between sites.

The national eHealth strategy published in June 2008 is focused on continuing this work and supporting the roll-out of systems locally when proven. Examples include the widely publicised *Emergency Care Summary* uploaded electronically from GP records, available to NHS 24, Out of Hours and accident and emergency services; and the associated development of a national Palliative Care Summary of essential palliative care information derived from GP systems, which contain explicit patient consent relating to such matters. In addition to major investments in hospital-focused patient management systems, the strategy also supports the greater use of video conferencing to enhance the ability of clinicians to work together, so they may effectively plan treatment for patients and improve information for patients and their carers.

“Specialists can provide support in a variety of ways, including visits, telephone advice, video-conferencing and out-patient clinics. It is also important to maximise the opportunities offered by new technologies, for example using cell-phone technology to monitor symptoms and provide self help information.”

Better Cancer Care Consultation Respondent

Telehealth

Telehealth, where deployed effectively, can improve the patient's experience of care by reducing the need for travel to major cities and hospitals to receive their care and treatment. It offers a range of options remotely via phones, (including mobile phones) and broadband, often involving video-conferencing. The Scottish Centre for Telehealth is supporting NHS Boards to pilot the use of telehealth to help redesign and improve patients' access to healthcare, no matter where they live.

Example of Good Practice

In May 2006, the Scottish Government supported the project team at the Scottish Centre for Telehealth by funding a pilot to test the 'proof of concept' in the use of tele-endoscopy. This used remote diagnostic technology to facilitate the examination of an airway for patients with symptoms of head and neck cancer. The pilot delivered a remote diagnostic service from Aberdeen to Shetland, following which, the clinics are now part of routine service delivery, with high levels of patient satisfaction being reported. In May 2008, this pilot was extended to deliver a remote diagnostic service from Raigmore to Stornoway and a local Speech and Language Therapist has been trained to perform endoscopy and facilitate the clinics. The final phase will see the delivery of a Head and Neck review appointment service to a local Community Hospital in Aberdeenshire.

The economic evaluation of the above project by Health Economic Research Unit (HERU) at the University of Aberdeen will be assessed by the Scottish Cancer Taskforce to ascertain wider roll out of the model of care. It is likely roll out of the model will be recommended if it is shown to be safe and effective, demonstrates better use of equipment and improved clinical outcomes for patients and reduces the number of patients who have to travel to major cities for specialist investigations.

We will:

- Form a new Scottish Cancer Taskforce to replace the existing Scottish Cancer Group
- Agree an annual work programme with key advisory groups to ensure that the actions set out in this plan are addressed and that the Scottish Government and NHS Boards have access to the latest advice and expertise
- Review the current network of groups that provide advice and guidance on cancer issues to ensure that this network is fit for purpose in supporting the delivery of this plan
- Provide national clinical leadership from the Deputy Chief Medical Officer, who will chair the Taskforce together with the three cancer lead clinicians from each Regional network and the Chair of the Scottish Primary Care Cancer Group
- Bring together the RCAGs, voluntary sector, NES, Directors of Workforce Planning and other stakeholders to address current and future workforce challenges
- Maximise the potential of the 4-tier model within radiotherapy with continued support from NES and other partners
- Support NES and NHS Boards to utilise the capability framework for cancer care
- Continue to involve and work with the eHealth programme, the networks and NHS Boards in the development of IT tools
- Assess the outcomes of eHealth and telehealth projects, which may improve service delivery and clinical outcomes for cancer patients.

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Useful Websites

Cervical Cancer and HPV

<http://www.fightcervicalcancer.org.uk/>

ISD Cancer Information Programme

<http://www.isdscotland.org/isd/183.html>

NHS Education for Scotland (NES)

<http://www.nes.scot.nhs.uk/>

NHS Scotland Publications (HDLs and CELs)

<http://www.sehd.scot.nhs.uk/index.asp?name=&org=%25&keyword=&category=6&number=10&sort=tDate&order=DESC&Submit=Go>

NHS Quality Improvement Scotland

http://www.nhshealthquality.org/nhsqis/CCC_FirstPage.jsp

North of Scotland Cancer Network

www.noscan.scot.nhs.uk

QIS Standards for Cancer Services (Core, lung, ovarian, breast and bowel)

<http://www.nhshealthquality.org/nhsqis/4118.html>

Scottish Cancer Coalition

<http://www.myelomaonline.org.uk/NetCommunity/Page.aspx?&pid=743&srcid=744>

Scottish Government

www.scotland.gov.uk

www.scotland.gov.uk/bettercancercare

SIGN Scottish Intercollegiate Guidelines Network

<http://www.sign.ac.uk/guidelines/index.html>

South East Scotland Cancer Network

www.scan.scot.nhs.uk

West of Scotland Cancer Network

www.woscan.org.uk

World Cancer Research Fund

www.wcrf-uk.org

GLOSSARY

Acute Services/Acute care	For a disease or illness with rapid onset, severe symptoms and brief duration
Barium enema	Enema in which a contrast medium (usually barium sulphate) is injected into the rectum and X-rays are taken to search for abnormalities
Benign	Not malignant and unable to spread in distant way beyond main tumour
Biomarker	A specific physical trait used to measure or indicate the effects or progress of a disease or condition
Bowel cancer	Colorectal cancer
Brachytherapy	Radiotherapy delivered using an internal radiation source close to the surface of the tumour. Used most commonly for gynaecological tumours
BSI	The British Standards Institution
Cancer	Abnormal growth of cells which tend to proliferate in an uncontrolled way and in some cases, metastasise. Cancer is not a single disease but a group of more than 100 different and distinctive diseases. Cancer can occur in any tissue of the body and has many different forms. Most cancers are named after the type of cell or organ in which they originated
Chemotherapy	The use of drugs which interfere with the process of cell division to destroy malignant cells
CNS	Clinical Nurse Specialist
Colonoscopy	An endoscopic (fibreoptic) examination of the colon
(CHCPS – CHPs/CHCPs) Community Health Partnerships/ Community Health Care Partnerships	CHPs have been established by NHS Boards as key building blocks in the modernisation of the NHS and joint services, with a vital role in partnership, integration and service redesign. They provide a focus for the integration between primary care, specialist services and social care and ensure that local population health improvement is at the heart of service planning and delivery
COSLA	Convention of Scottish Local Authorities
CT (Computed Tomography)	An x-ray technique using a scanner which takes a series of images across the body which can be viewed in 2D (dimensional) or 3D form
Cytogenetic	The study of chromosomes and cell division
Cytology	The study of cells
Cytology Screener	A person who assesses the sample slides in the cervical screening programme
Cytotoxic	Chemicals that are directly toxic to cells, preventing their reproduction or growth
DNA	Deoxyribonucleic Acid. The main repository of genetic information in all cells
E-Health	The use of electronic communication and information technology in the healthcare sector
Endoscopy	Visual inspection of a body cavity using an endoscope, which is a flexible viewing instrument
Enema	The injection of liquid into the rectum through the anus for cleansing, for stimulating evacuation of the bowels, or for other therapeutic or diagnostic purposes

Epidemiology	The branch of medicine that deals with the study of the causes, distribution, and control of health-related problems or disease in populations
Fields of View	The area that is visible (as through an optical instrument)
Flexible sigmoidoscopy	Inspection of the rectum and lower colon using a thin lighted tube called a sigmoidoscope
Health Technology Assessments	The HTA programme, part of the National Institute for Health Research, works to provide all those who make decisions in the NHS with high-quality information on the costs, effectiveness and broader impact of healthcare treatments and tests
Horizon Scan	The systematic examination of potential threats, opportunities and likely future developments, strengths and weaknesses to planning
HPV (Human papilloma virus)	The HPV is a risk factor for cervical cancer, transmitted through intimate contact, including sexual intercourse. Vaccines are now available to prevent infection to help prevent this type of cancer
HSE	Health and Safety Executive
Incidence	The number of new cases/episodes in a defined population within a given time period
Invasive	Cancer that can/has spread from its histological original site
ISD (Information & Statistics Division)	Scotland's national organisation for health information, statistics and IT services
ISO	International Organisation for Standardisation
Isotope	Radioactive material
Laparoscopic surgery	Minimally invasive surgery in which a camera and surgical instruments are inserted through a small incision
Leukaemia	The abnormal growth and development of the white blood cells
Life Circumstances	Determining or modifying factor(s) that affect a person's life
Linear accelerator	A treatment machine generating very high energy x-rays or electrons. Also called a LINAC
LUCADA	Lung cancer audit data analysis
Lymphoma	Cancer of the lymphatic system/lymph nodes
Malignant	Cancerous. Malignant tumours can invade and destroy surrounding tissue and have the capacity to spread
Mammogram	A diagnostic image of the breast
MCN (Managed Clinical Network)	The term Managed Clinical Network is used to refer to a way of working which relies on clinicians being part of a 'virtual' organisation and which actively involves patients in service design and focus

Melanoma	A tumour arising from the melanocytic system of the skin and other organs
Metastasise	Spread throughout the body
Molecular pathology	An emerging discipline within pathology which is focused on the use of nucleic acid-based techniques
Mortality	The number of people who have died from cancer and is usually expressed as the number of deaths each year in a specified area
Mortality rates	The number of people who die from cancer per 100,000 population
MRI (Magnetic Resonance Imaging)	An imaging technique based on magnetism, radio waves, and a computer to produce images of body structures. It provides superior soft tissue definition of many tumours compared with CT
NAG	The Scottish National Advisory Group on Breast and Cervical screening
National Services Division	Part of National Services Scotland, which plans and funds services on a national basis
Neoplasm	Abnormal new growth or proliferation of cells/tissue that shows a lack of cellular organisation and function. May be benign (non-cancerous) or malignant
NHS	National Health Service
Oncology	The branch of medicine that deals with cancer
Palliative care	Providing relief and support, but not cure
Pathologist	A doctor who specialises in identifying diseases by microscopically studying cells and tissues
Patient Pathway	The route that a patient will take from first noticing symptoms and contact with an NHS member of staff (usually their GP), through referral, to the completion of their treatment
PFI	Private Finance Initiative
Positron Emission Tomography (PET)	PET is a non-invasive diagnostic imaging technique that combines computed tomography and small amounts of a radioactive substance. It provides functional information about the tumour and its site and size
Predispose	To make more likely or render susceptible
Primary care	Health care provided by a medical professional (as a general practitioner, paediatrician, or nurse) with whom a patient has initial contact and by whom the patient may be referred to a specialist
QIS (Quality Improvement Scotland)	NHS Quality Improvement Scotland is a Special Health Board, acting as the lead organisation in improving the quality of healthcare delivered by NHSScotland
Radiotherapy	The use of radiation to destroy malignant tumours while minimising the damage to normal tissue
Regimen	A treatment plan that specifies dosage, schedule, duration of treatment

RNA	Ribonucleic acid. The nucleic acid that is used in key metabolic processes for all steps of protein synthesis in all living cells
Scottish Intercollegiate Guidelines Network (SIGN)	Improving the quality of care for patients in Scotland by reducing variation and outcome through the development of national guidelines containing recommendations for effective practice, based on current evidence
Screening	Examination of people with no symptoms to detect unsuspected disease
Secondary care	Medical care provided by a specialist or facility upon referral by a primary care physician
Second-line chemotherapy	Chemotherapy given for a tumour which has already failed to respond to a first chemotherapy regimen
Shared care	The establishment of partnerships between professionals and patients where they share a common goal
Stereotactic intracranial radiotherapy	Where radiotherapy is directed at brain tumours based on 3-dimensional imaging
Survival rate	The percentage of people still alive 1, 3, 5 and 10 years after they have been diagnosed with cancer. The 5-year survival rate is often quoted
Tertiary care	Highly specialised medical care usually over an extended period of time that involves advanced and complex procedures and treatments performed by medical specialists in state-of-the-art facilities
Triage	The process of sorting people based on their need for immediate medical treatment
Tumour	An abnormal mass of tissue that results from excessive cell division that is uncontrolled and progressive, also called a neoplasm. Tumours can be benign (not cancerous) or malignant
Two views	In two view mammography two x-rays are taken to examine each of the human breasts
UK NSC	UK National Screening Committee
Ultrasound	An imaging technique using high-frequency sound waves. Useful in the diagnosis of tumours
WHO (World Health Organization)	WHO is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends
X-ray	A type of radiation used for imaging purposes, which uses energy beams of short wavelengths at high energy used for treatment that can penetrate most substances except heavy metals

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